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ABSTRACT

This resource guide presents general information about disabilities and summaries of relevant federal laws. A question-and-answer format is used to highlight key features of the Education for All Handicapped Children Act (Public Law 94-142, reauthorized in 1990 as the Individuals with Disabilities Education Act); Section 504 of the Rehabilitation Act of 1973; Public Law 99-457; and the Americans with Disabilities Act. Then individual sections provide information on vision impairments, hearing impairments, speech impairments, physical disabilities, mental retardation, learning disabilities, multiple disabilities, emotional disorders, autism, and other health impairments. Information provided typically includes the nature of the impairment, severity factors, associated problems, aids and appliances, therapeutic or remediation approaches, simulation activities, and resources (books for both children and adults as well as organizations). Specifically discussed under physical disabilities and other health impairments are the following conditions: cerebral palsy, spina bifida, spinal cord injury, muscular dystrophy (Duchene type), juvenile rheumatoid arthritis, multiple sclerosis, brittle bone disease, and amputation. The guide also presents lists of general print and organizational resources, guidelines for use of less stigmatizing terminology, and suggestions for interacting with individuals with disabilities. (DB)

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COUNT ME IN

Resource Manual On Disabilities

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Introduction

Public Law 94-142, the Education for All Handicapped Children Act, now known as the Individuals with Disabilities Education Act (IDEA), has paved the way for many children with disabling conditions to be educated in a setting with children who do not have disabilities. For some students this means all day in the regular classroom; for others it means a few hours a day or some classes with children without disabilities.

Moving children with disabilities into the mainstream requires some preparation for the child with disabilities, the classroom teachers, and children without disabilities. While the child with disabilities and the teachers may be given a great deal of preparation, often very little is done to assist the other pupils in learning about disabilities and relating to their classmates, or people in general, who have disabilities in general. Frequently, there are fears about the disability, questions and comments about aids and appliances, and apprehensions about a child who is somewhat different.

Through training programs for adults and puppet show presentations for children, COUNT ME IN works to dispel the fears and myths that surround disabling conditions and to increase the understanding and realization that children with disabilities are very much like all other children.

PACER Center, Inc. has developed this manual to be used as a resource guide by volunteers who assist with COUNT ME IN presentations, by teachers whose classes view COUNT ME IN puppet shows, and by others who are interested in helping children learn about disabilities. It is our hope that COUNT ME IN presentations will awaken a curiosity in children and adults to learn more about people with disabilities.

The *COUNT ME IN Resource Manual on Disabilities* provides some very basic information about many disabilities. Included are many books and organizations which provide further information about particular disabilities and about equipment used by individuals who have disabilities. The danger of any brief summary is that some information is unintentionally minimized or omitted. Therefore, the reader is encouraged to keep in mind that this resource manual is intended to be used as a guide, not as a detailed authority, for general information about disabilities, for ideas on classroom activities, and as a reference for further study.

The summaries of P.L. 94-142 and several other important laws are included to give a brief overview of the rights afforded to children with disabilities and their families under the law. The process of identifying children with disabilities, conducting proper assessments to define each child's needs, and providing appropriate programs to meet those needs is extremely important. We hope that the inclusion of this information will provide encouragement to all individuals who are interested in children.

Laws That Affect Children with Disabilities

The Education for All Handicapped Children Act Public Law 94-142 (also known as The Individuals with Disabilities Education Act)

The Education for All Handicapped Children Act (EHA) was passed by Congress and signed into law by President Ford in November of 1975. When reauthorized in 1990, it was renamed the Individuals with Disabilities Education Act (IDEA).

In summary, it states:

> *"All children regardless of disabling condition, are entitled to a free, appropriate public education in the least restrictive alternative."*

What is meant by "all children with disabilities"?

Any child (in Minnesota), from birth to 21 or upon completion of high school, who has a disability, regardless of severity, is entitled to a free, appropriate educational program.

P.L. 94-142 and P.L. 99-457 (the Individuals with Disabilities Education Act Amendments of 1986) require that all districts identify, assess, plan and monitor **all** preschoolers who have disabling conditions. (See additional information on "Locating Children with Disabilities" on page 3.)

What disabling conditions are included under the law?

The disabilities included are:

- hearing impairments
- vision impairments
- deaf-blind and multiple disabilities
- speech/language disorders
- mental retardation
- physical disabilities
- emotional/behavioral disorders
- learning disabilities
- health impairments (epilepsy, diabetes, etc.)

How are special education services provided "free of charge"?

The public school district in which the child's parents or guardians reside is financially and legally responsible for that child's special education program and related services. Children with disabilities who attend non-public schools are also eligible to receive special education services through the public school system.

How does the school district determine an "appropriate" education?

The law states that every school district shall:

a. **Assess** each child who has disabilities to determine his or her strengths and weaknesses and specific educational needs.

b. Plan an **individual educational program (IEP)** for each child, based on each need as determined by the assessment. The IEP should be updated each year to assure that the student is receiving appropriate educational service. Parents/guardians must be invited to take part in the IEP meetings.

c. Establish a plan for the **periodic review** of the child's progress (meeting dates). Parents are not automatically included in review meetings. If they wish to attend, they should ask to be invited.

At least one review is required annually under Minnesota law. Parents and/or school may request additional meetings regarding the child's progress if they feel the meetings are needed.

d. **Reassess** the student every three years (minimum) to determine the student's progress and needs. Parents and/or schools may request reassessments more often, if needed.
e. Carry out all procedures to assure that parents are afforded all **due process** rights. If a disagreement exists concerning a child's assessment or educational plan, parents and schools have the right to utilize the appeal process (conciliation, hearing, and appeal).

How are parents involved in this process?

Parents have the right to:

a. Be notified in writing of any plans to assess their child or change the child's educational program.
b. Request an assessment.
c. Participate in planning of the individual educational program (IEP).
d. See the child's records and obtain copies of those records.
e. Request a conciliation conference (an informal conference) with school personnel to discuss disagreements on any part of the educational program.
f. Request a due process hearing, an appeal to the State Commissioner of Education, or an appeal to district court for unresolved problems.

What is meant by an appropriate educational program?

The school district shall provide the education deemed necessary as a result of the assessment and decisions made at a team staffing.

The school district shall educate each child with disabilities in as normal a setting (with children without disabilities) as is possible and appropriate.

Schools should be flexible in programming for students. A continuation of services should be available to meet the changing needs of each student.

Who must identify children with disabilities?

P.L. 94-142 states that every school district must utilize procedures which insure that all children (birth to 21) residing within their jurisdiction who have disabilities and are in need of special education and related services are identified, located, and evaluated. Included are children in all public and private agencies and institutions who live within that jurisdiction, as well as children of preschool age. This process of identifying children with disabilities is often called **child find.**

The importance of good systems for the identification and assessment of young children with disabilities (birth to 3) cannot be over-emphasized. By identifying children as early as possible, adults who work with young children may offer help in such a way as to enhance the child's potential and minimize some of the negative effects of the disability. Identification of a disabling condition in a child is only the first step in the process of assessing the specific needs of the child and planning an appropriate program.

How are children with disabilities located?

Identification activities can include the use of school census, screening, general public information, and referrals from parents, teachers, doctors, agencies or other interested people.

Census - All school districts in Minnesota* are required to take an annual school census to identify all children, ages birth to 21, including those who have disabilities.

* Minneapolis, St. Paul and Duluth are cities of the first class and are not required under law to have an annual census.

Screening - Screening refers to a method of identifying possible disabilities by giving children a series of health or educational tests. Some examples of screening tests are those given at periodic health check-ups or those given by schools to three-year-old children the year prior to kindergarten to check vision, hearing, motor skills, and coordination. Routine screening such as for vision, hearing, or scoliosis (curvature of the spine) are conducted at various grade levels in elementary schools.

Screenings do not provide enough detailed information to determine that a disability does indeed exist. If a child does not pass screening tests, assessment is the necessary next step.

Public information programs - Information about various disabilities through media sources (TV, radio, newspapers, etc.) may help parents or others to recognize a disability or particular delay in a child.

Referrals by parents - Referrals are the means by which a parent or other interested person may request that an assessment be arranged for any child. A parent is the primary observer of a child, the one who sees the child daily in many different situations, and may often be the first to suspect that a problem exists such as a developmental delay, a hearing problem, a learning disability, or some other disability. A parent may request an assessment for the child at any time a disability is suspected.

Referrals by teachers - Classroom teachers can be most important in making referrals because of their daily contact with many students and their ability to recognize a problem which may indicate a student has disabilities. Teachers should be aware of signs that indicate a disabling condition.

Referrals by medical personnel and agencies - Medical personnel, especially pediatricians or pediatric nurses, may often detect a condition that could warrant the need for special education. These professionals often encourage the parents to seek out an assessment from the school or from a medical facility, whichever is most appropriate. Persons in agencies such as Head Start programs, day care centers, group homes, scouts, or park programs may suspect a problem or disability in a child. It is appropriate to discuss the observation with the parent or school, whichever is appropriate, and have the child referred for assessment.

What is the assessment process?

Each school has its own procedure for referring a child for assessment whenever a problem is identified. If the child fails a routine school screening, the school should automatically indicate to the parents what follow-up assessment is necessary and explain their way of providing for it.

If the teacher suspects a disability or need for assessment, the school usually has a referral form that can be completed by the teacher and given to the designated person, such as a principal or special education director before making a referral. There are many resources available to help teachers learn more about disabilities.

Sometimes a teacher may find it necessary to initiate the referral process for a particular student even though the school district does not presently have the necessary resources to serve the child. The intent of the law is clear. All children with disabilities shall be served with appropriate programs. Teachers, parents, and all advocates for children must be concerned if school districts adopt policies that are in conflict with the intent of the law.

When a parent wishes to request an assessment, the first step is to notify, in writing, the child's home school. A letter should be sent to the principal or the special education director, with a copy to the classroom teacher. The letter should include information as to the nature of the problem, observations of parents and others, and reasons for wanting an assessment.

Within a reasonable period of time (10 school days), the school must respond to the parent's request for an assessment. If the school agrees to assess the student, it has 30 school days to complete the assessment.

P.L. 94-142 states that parents must be notified in writing by the school about the details of the assessment. The law requires that for an initial assessment, parental written consent must be obtained before the school can proceed.

The identification and assessment processes are extremely important if all children with disabilities are to be provided with a free, appropriate, public education. Teachers and parents play a significant role in insuring that all children with disabilities are located, identified and evaluated.

What is the least restrictive alternative?

The integration of children with disabilities into the everyday life of the public school has been greatly increased in the last decade, especially since P.L. 94-142 was passed. According to the law, children with disabilities are to be educated, to the maximum extent possible, with children without disabilities. This concept is known as the **least restrictive alternative**.

In the past, many children with disabilities were separated from their normal peers and kept in special classrooms for children with disabilities throughout their school years. Sometimes, the children in these classrooms had similar disabilities, or in some cases very dissimilar disabilities, but nonetheless children were segregated from the rest of the school population because of the fact that they had a disability. Thesechildren missed many opportunities for learning and development; they were categorized by what they couldn't do rather than by what they could do.

Mainstreaming (a term frequently used) is sometimes misunderstood. It does not mean that every child with disabilities will be spending all day in a regular classroom setting. A child should be placed with peers who do not have disabilities in the most appropriate way. For some, the academic challenge of a regular classroom is the best integration plan. Each child's program must be considered individually.

The COUNT ME IN project helps students develop positive attitudes about persons who have disabilities by dispelling fears and myths about handicapping conditions. Children and teachers have a chance to learn about disabilities, talk about their feelings, and realize that people with disabilities are "more like them than different."

Knowledge and understanding of individuals with disabilities can foster positive attitudes that will enable the *least restrictive alternative* to work, not just in the classroom, but also in the hallways and the neighborhoods, in every walk of life.

Section 504 of the Rehabilitation Act of 1973

What is Section 504?

Section 504 of the Rehabilitation Act of 1973 is often referred to as the Civil Rights Act for Persons with Disabilities. Its provisions affect a wide range of programs including education. Basically, the Rehabilitation Act makes it illegal for any agency or organization that receives federal funds to discriminate against a person with disabilities solely on the basis of his or her disability.

All public and private organizations receiving federal money must take special steps (including making programs accessible) to make it possible for people with disabilities "to learn, work, and compete on a fair and equal basis." Non-compliance can result in a cutoff of all federal support to the agency or organization.

What disabilities are covered by Section 504?

The law prohibits discrimination against persons whose disabilities are severe enough to substantially limit one or more of the major life functions. Disabilities covered include speech, hearing, visual, and orthopedic impairments; cerebral palsy; epilepsy; muscular dystrophy; multiple sclerosis; cancer; diabetes; heart disease; mental retardation; emotional illness; and specific learning disabilities such as perceptual disabilities, dyslexia, minimal brain dysfunction, and developmental aphasia.

How does Section 504 apply to education?

Section 504 makes many of the same requirements for education of children with disabilities as does P.L. 94-142. The basic requirements are that:

- No child with disabilities can be excluded from a public education because of disability;
- Every child with disabilities is entitled to a free, appropriate education, regardless of the nature or severity of disability;
- Children with disabilities must be educated with students who do not have disabilities to the maximum extent appropriate to their needs;
- Evaluation (assessment) procedures must be improved to avoid the inappropriate education that results from misclassification of a student;
- Procedural safeguards must be established so parents and guardians can object to evaluation and placement decisions regarding their children;
- State or local education agencies must locate and identify unserved children with disabilities.

Why do we need the additional protection of 504?

Although the provisions of Section 504 relating to education are similar to those of P.L. 94-142, Section 504 provides the additional sanction of possible withdrawal of all federal funds from an agency that is found not to be in compliance. In addition, as a civil rights act, Section 504 offers an additional avenue of appeal that may be helpful if the remedies under P.L. 94-142 do not resolve problems.

What requirements are made for accessibility?

Section 504 requires that all programs receiving federal funds must be accessible to persons with disabilities. New facilities constructed after June 3, 1977 must be designed to meet the accessibility standards of the American National Standards Institute. Existing programs also must be made accessible, but this does not mean that every building must be totally remodeled. The emphasis is on *program* accessibility. An existing program may be considered to be accessible if the portions of the facilities used by persons who have disabilities are

made accessible or if other means are employed to make the program accessible, such as assigning students to accessible facilities or using aides to assist the students. Such modification, however, cannot result in the segregation of persons with disabilities from persons without disabilities who are involved in the program.

Accessibility modifications can be made at reasonable cost, and technical assistance is available to institutions to help them design the changes in practical ways.

How long has Section 504 been in effect?

The regulation went into effect June 3, 1977. Programs operating in existing facilities where non-structural changes were needed had to be in compliance by August 2, 1977. In cases where structural changes were needed, the agencies were required to submit by December 2, 1977, a plan to make the changes. By June 2, 1978, all federal fund recipients were required to complete a self-evaluation process to determine whether they were in compliance with Section 504, in consultation with individuals with disabilities and organizations. Public elementary and secondary schools were required to meet the "free, appropriate education" requirements by September 1, 1978. By June 2, 1980, all needed structural changes must be made in existing facilities that receive federal funds.

How can a complaint be filed?

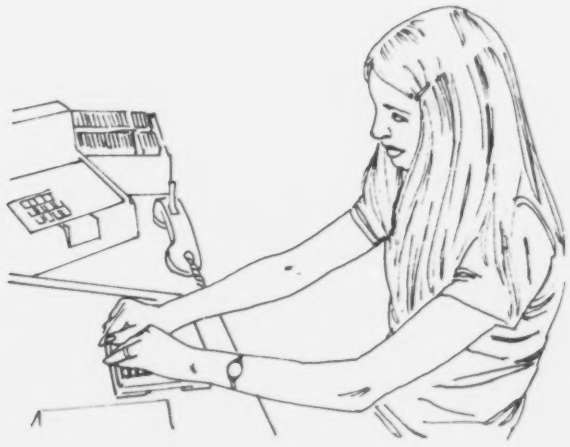
If a person believes that any aspect of Section 504 has been violated (discrimination on the basis of disability in any program funded by the federal government), he or she may initiate a complaint to the Office for Civil Rights.

The complaint should be in the form of a letter explaining who was discriminated against, in what way, by whom or what institution; when the discrimination took place; who can be contacted for further information; writer's name, address and telephone number; and as much background information as possible.

The letter should be addressed to: *Region V Office of Civil Rights, Department of Education, Room 700C, 401 S. State St., Chicago, IL 60605-1202. Telephone: (312) 886-3456*

The federal office is: *Department of Education, Room 5000, Switzer Bldg., 400 Maryland Ave. SW, Office for Civil Rights, Washington, DC 20202.*

In the case of complaints against school districts, Section 504 requires each school district to have a Grievance Coordinator, an impartial person who will take the complaint and steer it through the system. The requirements are spelled out in Section 504, 45, Code of Federal Regulations 84.7.



The Individuals with Disabilities Education Act Amendments of 1986 (Public Law 99-457)

In October, 1986, President Reagan signed into law this important piece of legislation, which:

- mandates special education services for children with disabilities ages three to five and
- creates a new discretionary program to address the special needs of infants and toddlers with handicapping conditions and their families (Part H).

By recognizing the positive effects of early intervention and family support services on the development of young children with handicapping conditions, this law takes steps to enhance their development, minimize their potential for developmental delay, minimize the likelihood of institutionalization, and enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities.

What are early intervention services?

Early intervention services are defined as developmental services which are provided under public supervision, at no cost (except where federal or state law provides for a system of payments by families) by qualified personnel. These may include:

- family training and home visits;
- physical and occupational therapy;
- psychological services;
- health services necessary to enable the infant or toddler to benefit from other early intervention services;
- case management, which assists families in gaining access to services, receiving services on a timely basis, and coordinating early intervention and other services.

States can expand services

Part H of P.L. 99-457 offers financial incentives to states to:

- develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for all infants and toddlers with disabilities and their families;
- help coordinate payment for these services from all public and private sources; and
- expand and improve existing services to provide quality early intervention services.

Minnesota and a number of other states, for instance, have expanded the federal mandate for special education services to cover children beginning at birth.

Who qualifies?

Infants and toddlers qualify for services under P.L. 99-457 if they:

- are experiencing delays in cognitive, physical, language and speech, or psychosocial development or self-help skills and qualify for service in Minnesota; or
- have a diagnosed physical or mental condition which may result in developmental delay (each state must define "developmental delay" and may include children "at risk" for developmental delays).

Emphasis is on families and interagency cooperation

A significant result of P.L. 99-457 has been the development of an Individualized Family Service Plan (IFSP), which designs services for the child with disabilities in the context of the whole family, taking into account its unique strengths and needs

as well as the unique needs of the child. The IFSP is a process as well as a document and is developed by the parents together with professionals. The document must be updated at least every six months and reviewed once a year.

Another important aspect of this legislation is its focus on interagency cooperation. A State Interagency Coordinating Council, appointed by the Governor, plays a central role in developing a coordinated system of services. Persons who can serve on this body include parents, professionals and representatives from education, health, human services and other agencies.

Thus, this law establishes and helps to fulfill a federal commitment to serve those most vulnerable young children who require special care.

The Americans with Disabilities Act

The Americans with Disabilities Act (ADA) was signed into law by President Bush on July 26, 1990. It provides civil rights protections to individuals with disabilities that are like those provided to individuals on the basis of race, sex, national origin, and religion. These protections are in place regardless of whether an office, business or agency receives federal funding.

The ADA guarantees equal opportunity for individuals with disabilities in the areas of:

- employment
- public accommodations
- transportation
- state and local government services
- telecommunications

Different provisions of the ADA (such as when buses or trains must be accessible) take effect over a period of years.

The main impact of the ADA is not on education in elementary and secondary classrooms but on adult life and "education" outside of the classroom. (An outline of the ADA is available from PACER.)

Vision Impairments

Visual disorders fall into three basic categories:

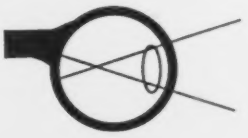
- **visual malfunctions** which can be corrected with lenses;
- **visual impairments** which adversely affect sight even with corrective lenses; and
- **severe vision impairments** which affect sight to such an extent that alternative methods must be used to read and travel.

What is vision impairment?

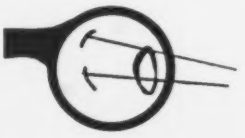
P.L. 94-142 defines visually handicapped as "having a visual impairment which, even with correction, adversely affects a child's educational performance." The term includes both children who are partially seeing and blind.

Hyperopia, myopia, and astigmatism are all common vision malfunctions which can usually be corrected. The drawings below illustrate these conditions.

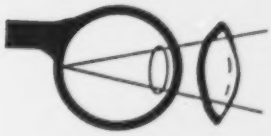
Hyperopia



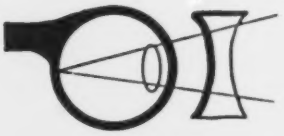
Myopia



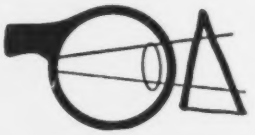
Astigmatism



Hyperopia (A)



Myopia (B)



Astigmatism (C)

Farsightedness (hyperopia) occurs when images fall in back of the retina instead of directly on it. **Nearsightedness** (myopia) is the result of images which fall in front of the retina. Hyperopia is corrected by a convex lens (A) and myopia is corrected by a concave lens (B). When two adjacent portions of the cornea have different curvatures, the result is **astigmatism.** A lens that bends nonfocusing light rays corrects astigmatism (C).

Visual acuity or the ability to see objects can be measured using the Snellen Eye Test and is reported in the form of a fraction. Normal vision is 20/20. A person is considered to have 20/70 vision if, when standing 20 feet from a Snellen Chart, he or she can only identify the same symbol that the normal eye would be able to identify at 70 feet or more.

In other words, **visually handicapped** means an inability to use vision — at all or to some degree — the way children with normal or correct vision use their sight to learn.

The term **partially seeing** is used to refer to a loss of visual acuity in the range of 20/70 to 20/200 with correction. To these persons, objects may look dim, blurred, or out of focus. Some lack peripheral vision or see only those things directly in the center of their line of vision. This is called **tunnel vision.** Children who are partially sighted can still use their vision aided sometimes with magnifiers or other similar devices.

The term **blind** is used to refer to persons who are totally without vision or who have light perception. They must rely on hearing and touch as their chief means of learning and use alternative techniques to

read, write or travel. These techniques include braille, white canes or guide dogs, aids and appliances marked in braille and other methods to gain information (such as cassette tapes, Talking Books and records) which persons with sight gain through their vision. Using these alternative techniques, persons who are blind can lead independent lives.

The legal definition of blind includes a "visual acuity of 20/200 or less in the better eye after correction, or severely-reduced peripheral vision (tunnel vision)." The definition includes not only persons who are totally without vision (that is, unable to distinguish light from dark or with no perception) but also those who have some vision in one or both eyes.

Ninety percent of people referred to as blind do have some remaining vision.

Causes of partial sight or blindness:

Some of the causes of vision impairments are listed below:

Amblyopia - Dimness of vision without any apparent diseases of the eye; usually the result of not using an eye ("lazy eye") in order to avoid the discomfort of double vision caused by a muscle problem.

Congenital cataracts - A clouding of the lens of the eye which reduces the amount of light received at the retina. Cataracts most often occur in only one eye. It can progress to the point of interference with vision. The cataract can often be surgically removed and corrective lens or contact lens can be worn. The chance of perfect vision is contingent upon other abnormalities also associated with the cataracts. The most frequent cause of cataracts in children is congenital.

Diabetes - A disorder involving defective metabolism of glucose and other substances which may result in degenerative eyesight.

Glaucoma - A condition in which the normal fluid of the eye does not drain properly, causing increased pressure within the eye. The increased pressure causes damage to the optic nerve resulting in severe loss of sight or tunnel vision. It can be treated.

Maternal syphilis - A very uncommon cause of blindness in recent years because many states now require that silver nitrate eye drops be given to newborns immediately after birth to prevent loss of vision.

Retinopathy of Prematurity (ROP) was formerly known as **Retrolental Fibroplasia** - A disease of the retina in which a mass of scar tissue forms in the back of the lens; usually affects both eyes and can cause a complete loss of sight. The high concentration of oxygen needed to keep premature babies alive is the major cause of this condition.

Retinitis Pigmentosa - A condition in which retinal function progressively worsens. Side vision usually decreases before central vision.

Retinal detachment - An eye condition in which a hole in the retina has allowed fluid to leak in behind the retina and push the retina off the back of the eye. Vision can be lost, but surgery can correct the situation.

Trachoma - An infectious disease of the eye causing scarring of the cornea, which reduces vision to light perception only.

Some children with eye problems may have other impairments caused by a specific disease or disorder such as prenatal German measles (Rubella) or malignancies such as retinal blastoma.

Vision impairment, in and of itself, does not impair intelligence or hearing. Vision impairment or blindness does not connote helplessness, inferiority or dependence.

The Minnesota Department of Education estimates that 337 children (ages birth-21) in the state were receiving some type of special education services in 1990 because of visual disabilities. Nationwide, visual impairments are found in approximately one student in 1,000, and approximately three out of ten of those students must use alternate methods of learning.

Signs of possible eye trouble in children

Behavior

- rubs eyes excessively
- shuts or covers one eye, tilts head or thrusts head forward
- has difficulty in reading, holds work close to eyes
- blinks more than usual or is irritable when doing close work
- unable to see clearly at a distance
- squints eyelids together or frowns

Appearance

- crossed eyes
- red-rimmed, encrusted, or swollen eyelids
- inflamed or watery eyes
- recurring styes
- nystagmus or wandering eye

Complaints

- eyes itch, burn or feel scratchy
- cannot see well
- dizziness, headaches, or nausea following close eye work
- blurred or double vision

The above information on the signs of possible eye trouble in children was used with the permission of the National Society to Prevent Blindness, New York, NY 10016.

Aids and appliances

There are many aids and appliances available to a person with limited vision to enable him/her to travel independently, read, and do most of the ordinary tasks of daily living.

Travel aids

Today most people who are blind use a white cane to gain information about the area where they are walking. Using a cane properly, people who are blind can travel on their own wherever they need to go.

The cane is straight and usually made of metal or fiberglass with some nonskid padding at the top for gripping. Rigid and nonrigid (folding, telescopic or screw-together pieces) are available with metal, nylon and light-sensitive tips. Adults who are blind use canes about shoulder-height or 4-5 feet long depending on the person's height and stride. Canes for children should be shorter. The blind person taps back and forth in an arc about the width to the outside of their shoulders.

Using the white cane in this way originated in the late 1940's with veterans who were blinded in World War II.

Many areas have teachers especially trained to help blind people learn how to travel in their community, to cross streets, to read maps, to negotiate traffic, to ride public transportation and to learn other necessary travel skills. Most people who are blind keep their white canes with them the majority of the time when outside of their own homes. While a person sits in class or at a desk, the cane might lie on the floor nearby or in another convenient spot.

A specially trained guide dog can also be used for travel but is less frequently used since techniques for cane travel have been developed. The dogs are trained at a school. The owner is also trained in techniques of using a guide dog. The dog on a leash walks slightly ahead of the person who is blind so the person can learn from the movement of the dog about steps and other obstacles. The person who is blind directs the dog, but the dog is trained to disobey a particular command if that movement would endanger his master's life (e.g., walking in front of a car).

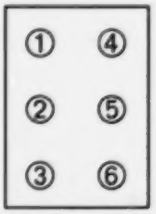
Guide dogs do require care and can become sick or injured just as any animal might. Many people who are blind feel that a cane can do the same things a dog can without the associated problems of animal care.

Learning aids

Many alternative methods of learning have been developed for people without enough sight to use visual methods.

Braille - A system for reading and writing, developed in 1824 by a 15-year-old French boy, Louis Braille, who was blind. Braille is composed of raised dots arranged in various combinations to represent single letters or entire words. Braille is read with the fingertips and can be written with a brailler (similar to a typewriter) or with a slate and stylus. The pointed stylus is used to punch dots into heavy paper using a braille slate as a guide.

The basic "Braille Cell" is two rows of three dots each. Each letter or number is composed of a certain combination of these dots. Some common words and abbreviations are denoted by braille contractions.



Braille Cell

There are three "grades" of braille.

Grade one has all letters in most words included.

Grade two is a shortened form with many contractions. It can be read faster and requires less space.

Grade three braille is used for personal note taking.

Nemeth braille is scientific/mathematical notation. It takes some practice to become a good reader of braille, as it does with reading of print. The learning process is somewhat the same. The beginning reader is taught to associate a certain symbol with a letter sound or a word meaning. When learning braille, the symbol is tactile rather than visual.

Braille books are large and quite expensive to produce. Most states (including Minnesota) have libraries of braille material which can be borrowed by a person who is blind. By U.S. law, books for persons who are blind can be mailed free of charge.

Twin vision books - Books available with both braille and print words and pictures in print and raised form. People can read them to sighted and blind children.

Auditory materials - Many persons who are blind, especially those blinded later in life, rely solely on auditory materials. Others use them in addition to braille materials. Here is a brief description of some of the many materials available:

- talking records
- talking books (tapes of books available from state libraries that can be adjusted to play at a rate faster than normal speech)
- talking calculator
- talking watches and clocks
- Kurzweil machine (an electronic device which scans a printed page and produces an audible reading of the material.

Technology - Computers can be adapted for use by those who are blind. A variety of ways are used such as: voice synthesizers which provide spoken rather than printed readouts; braille printers that can hook up to a computer; portable computer keyboards; talking software; braille n' print computers; and keyboards that can be brailled or otherwise adapted as the needs of the person dictate (some printers are able to print out braille). There are pocket braillers, portable braillers, and braille n' speak units, too. Each of these devices has particular functions that fit the needs, skill abilities and the setting in which it is used by the person who is blind.

Opticon - A device that translates printed material into electrical impulses which are read with the fingertips. The reader passes a scanner over a regular printed page and feels the electrical pattern (which is not braille) with his other hand.

Readers - Many older students who are blind, particularly at the college level, use volunteer or paid readers to accomplish their reading assignments.

Low vision aids - Such devices as closed circuit television which enlarges print and various magnifiers are used by persons with some vision to read print. Depending upon the specific nature of the visual disability and its effect on functional vision, these aids are helpful to some persons, but for others they are not. Often, these aids are useful in combination with braille or tapes. Some books are also produced in large print editions for primary and secondary levels. However, they are not usually available at the post-secondary level because of the expense of production.

Watches, clocks, games and cooking equipment are also available with large print.

Daily living aids

There is a wealth of adapted materials used by people who are blind, and many blind people create their own adaptations to meet their individual needs. Catalogs of materials for the blind list such items. For instance, the Products Catalog for People with Visual Problems is available from the American Foundation for the Blind, Consumer Products Dept., 15 W. 16th St., New York, NY 10011 or call free at 1-800-232-5463 or (1-800-AFBLIND).

A few of these materials are listed as examples:

- talking thermometer
- tactile watch (with dots)
- low vision watch (large numerals)
- magnifier for sewing machine (attaches to needle area)
- chiming clock
- raised numeral clocks
- timer with raised dots
- braille Scrabble, Monopoly, playing cards
- tactual checkers (recessed squares on board)
- chess board (with raised black squares drilled for pegged chess pieces)
- dominoes (with raised black dots)
- pegboard Tic-Tac-Toe
- pie cutting guide
- electronic liquid level indicator
- electronic metronome (with tactual scale)
- braille instructions and cookbook
- coin organizers
- braille large print labeller
- check & envelope guides for writing
- carpentry tools marked in braille
- color tags for clothing

Recreational adaptations

Sports - People who are blind ride bikes, ski, swim, jog, bowl, play baseball and other games often with only minor adaptations. These adaptations are more often individually made to the needs of the particular person than standardized. Children with blindness, because of the low incidence of their disability, usually play with playmates who are sighted and make unique adaptations in order to participate. Many childhood games can be enjoyed if participants are just required to tell what they are doing or what is happening.

Beep baseball - is played with a large baseball with an electronic beep and two bases that make a buzzing sound. A pitcher who is sighted throws the beeping ball to the batter who is blind. If the batter who is blind hits the beeping ball out into the field, he runs to whichever base is making a sound (first base or third base). When the ball is hit, the five fielders who are blind drop to their knees and block the ball with their bodies. If the batter makes it to the buzzing base before the fielders pick up the ball, he or she gets a point. But if fielders pick up the beeping ball before the batter makes it to the buzzing base, he or she is out.

Balls with bells inside - are available in several sizes.

Basketball - is usually adapted by individuals in unique ways. A regulation ball is easily heard, and baskets can be identified with different noises.
Many people who are blind cross-country ski with a companion who is sighted. There are special guide programs at downhill ski areas. Bowlers who are blind can use a guide rail. Some people who are blind roller skate, ride horses and swim. Some people who are blind ride tandem bicycles with a sighted friend. Children can ride regular tricycles with supervision.

Educational methods

Most students who are blind would probably receive instruction in reading and writing braille from a vision teacher at school. These teachers often travel to several schools. That teacher would obtain the child's classroom materials in braille or on tape. The student would learn braille as the child who is sighted learns print. Many students who are blind learn to use a keyboard (such as braille n' print) so a teacher who is sighted can easily correct their work. The input is braille; the output is print.

Feelings about being blind

Laurie, a 14-year-old girl who lost her vision in mid-childhood, describes her feelings about being blind in a book, *Feeling Free* (Addison-Wesley Publishing Co., Inc., Reading, MA 1979). She states:

> I always wanted to be like everyone else, but when I went blind I just figured everyone was going to treat me differently. But it's not like that at all. In fact, sometimes now it makes me feel good to know that I'm not like everyone else. I have something that's different.
>
> Some things make me really uncomfortable. One thing that really gets me upset is when people talk about me as if I weren't even there! I can't even describe how angry that makes me. Like sometimes someone will ask my mother, 'And how's Laurie?' and I'm standing right there! I'm not invisible.
>
> My mother just says, 'Why don't you ask her?'
>
> I don't think I'm really that different. Sure I have a disability, but I also have as many friends as anyone else. I go to a public school just like anybody else, and I do almost everything I want to try. I just don't think of myself as being different.
>
> I guess I'm just like most 14-year-old girls.
>
> Sometimes when I'm walking with my cane I get scared. I'm afraid that I might walk off a curb or go up somebody's driveway or something. Also, when most people cross the street they can usually look for cars that might be coming. I have to listen.
>
> I don't always like to use my cane. If I'm going to the store with one of my friends, it makes me feel funny to be carrying it around. It makes me feel awkward.
>
> When I get older, I want to get a guide dog. I'd get one now if I could, but you have to be 18 years old first. I guess they figure that an adult will take care of the dog better, and that it would be easier to teach an adult how to work with a guide dog than it would be to teach a kid.
>
> I like being as independent as possible. It's probably my biggest thing. I'd much rather try something myself than have someone do it for me. If I can't do it, then I'll try asking for help.
>
> I think that I'm going to make it, if you know what I mean. I think that everything's going to be all right for me. I'll be able to do more and more things on my own. I won't always have to have somebody else around. I'll be independent.

Puppet used to portray vision impairment

The puppet who portrays a child who is blind in COUNT ME IN programs has been blind from birth. She has congenital cataracts. Her name is Gina. She carries a white cane, wears a braille watch, has braille books and games. She enjoys playing the drums and riding a tandem bike with her friends.

Questions our puppet has been asked

Do you always use your white cane?

> No, only when I'm going to a place I don't know well. I don't use it at home most of the time, because I know where everything is! In school, although I know where things are, I like to have my cane with me in case teachers or kids move things around.

If you lose your white cane or something else, how do you find it again?

> I look around the places where I usually leave it, or I try real hard to remember where I left it. Otherwise, I ask someone for help.

Will you have that white cane all your life?

As long as I want it. But as I grow, I get new ones, because a cane has to be the right size for my height. There are fold-up canes, sectional canes and fiberglass canes that are right for my travel needs, too.

Will you ever get a seeing eye dog?

Maybe. I have to be 18 -years -old to have a seeing eye dog. When you get a guide dog you have to go to school to learn how to use and care for the dog properly.

How can you tell where food is on your plate?

When I was younger, I liked to pretend my plate was like a clock. Mom would put my meat at 12:00, potatoes at 3:00, vegetable at 6:00, and salad at 9:00. But now that I'm older, I can tell what foods are by their smell and by feeling them with my fork.

How can you pour a glass of juice?

I just put my finger over the edge of the glass to tell how full it's getting. We use a certain pitcher at home for orange juice, another for milk, so I can tell by the feel of the pitcher what's inside.

How can you tell what people look like?

Well, there are several ways. If it's a close friend, I ask to touch their hair and face and then I have some idea. But usually I listen to the voice and imagine what a person looks like. I figure a person who sounds nice must look nice. I also ask people to tell me what they look like.

What sports can you play or what outside activities can you do?

I like many different sports. Most can be adapted so I can play, too. I like to ride a tandem bicycle with my brother or friends. Cross-country skiing is fun, and I love to bowl.

Are you scared being blind like I'm scared of the dark?

No. I've learned how to get around and how to listen really well, so being blind doesn't scare me.

Do you have hobbies like other kids?

Sure. I love to read. I get braille books through special libraries. I have quite a tape and record collection, and I love to play the drums.

Can you really hear better than other people?

No, but I do need to pay better attention to the things I hear, because that is a very important way I learn about things.

Simulation activities for blindness

For many people the idea of being blind is quite scary. Some cannot imagine how they could accomplish quite ordinary tasks without seeing. Most people who are blind will tell you that they are not frightened, and that with practice, most tasks are quite easy. While we believe it is important to help children understand how people who are blind accomplish various tasks, it is important to stress during these experiences that people who are blind are not frightened and do not have extraordinary abilities.

1. **TOUCH AND FEEL BAG** (preschool and primary grades)

   EQUIPMENT: Cloth or paper bag, 3-4 items familiar to children, one or two items not so familiar.

   WAYS OF PLAYING GAME: Seat children in a circle.

   a. Put 6 items in bag. Name one item and have child find it by "feeling." Take it out for all to see. Pass bag on.
   b. Put one item in bag. Pass bag around and have each child tell what he or she thinks it is by just feeling.

c. Put very unusual item in bag. Have one child describe what it feels like and have rest of class guess what it is.

2. **GUESS WHAT THAT IS?** (preschool and elementary)

EQUIPMENT: A recording of sounds (like cars honking, etc.)

Tell the children to close their eyes and pretend they are standing on a curb (or standing in a doorway). Like a person who is blind, each must listen carefully to hear what's going on, what's going by, what animal that is, etc. What would they learn/know from the sounds?

3. **WHAT'S GOING ON?** (elementary)

EQUIPMENT: Movie and projector.

Watch a movie without any light projection. Discuss how students think the characters and scenery look. Show the movie again with projection, and compare notes.

4. **WRITING BRAILLE** (elementary)

EQUIPMENT: A blunt pencil and heavy paper for each participant. A card with the braille alphabet. A pencil can be used to punch braille dots into a piece of construction paper. You might have the children read each other's braille notes.

5. **TELL ALL** (elementary)

EQUIPMENT: None

Have one student volunteer to sit in a central place in the classroom with eyes closed for a certain period and afterwards report what they could tell about events during that time.

6. **TRY IT OUT** (all ages)

EQUIPMENT: Aids and appliances used by blind and partially sighted persons (e.g., slate and stylus, bell ball, braille games, braille books, white cane).

Let students try equipment used by the blind. A yard stick or umbrella can substitute for a white cane.

7. **TASTE TEST**

EQUIPMENT: Related foods such as apple — pear; orange — grapefruit; 7-up — Pepsi; Graham cracker — vanilla wafer.

Have children try to identify these foods by tasting and smelling only, not by seeing or feeling. Have them talk about how much they could tell about the foods.

This information on vision impairments was reviewed and updated by Joyce E. Lindgren, P.H.N., M.P.H., consultant who deals with family issues related to children with special needs, and parent of several children with vision impairments; and by Judith Normandin, special education teacher for persons who are visually impaired.

Resources

Books for children

(P = Primary, M = Middle, U = Upper grade level recommendations)

Aiello, Barbara; Shulman, Jeffrey. *Business is Looking Up*. Twenty-First Century Books, 1988. (P, M)

Bowden, Nina. *The Witch's Daughter*. Philadelphia, PA: Lippincott Press, 1966. Jewel thieves on an island leave Janey who is blind, her brother, and a friend in a dark cave. Janey hears the way out. (M, U)

Brom, Elizabeth. *One Day I Closed My Eyes and the World Disappeared*. New York, NY: Dial Press, 1978. (P)

Charles, Ray; Mathis, Sharon Bell. *Ray Charles*. New York, NY: Thomas & Crowell, 1973. Story of a jazz musician who is blind and has many competencies. (M, U)

Clewes, Dorothy. *Guide Dog*. New York, NY: Coward Press, 1965. Roley finds it difficult to accept a seeing eye dog, because his blindness occurred from a dog lunging at him causing him to drop an explosive package. (U)

Cohen, Miriam. *See You Tomorrow, Charles*. Green Willow Books, 1983. A first grade class begins to accept the new boy, Charles, who is blind. (P, M)

Corn, Anne L.; Cowan, Chris M.; Moses, Elaine. *You Seem Like a Regular Kid to Me!* American Foundation for the Blind, 15 West 16th Street, New York, NY 10011, 1988. (M)

Davidson, Margaret. *Louis Braille, The Boy Who Invented Books for the Blind*. New York, NY: Hastings House Publishers, Inc., 1971. (M, U)

Delaney, Ned. *Two Strikes, Four Eyes*. Houghton, Mifflin Co., 1976. Toby is a mouse who loves baseball but cannot see without his glasses. A fantasy for young children that deals with teasing and social fears. (P)

Goodsell, Jane. *Katie's Magic Glasses*. Boston, MA: Houghton, Mifflin Co., 1972. Katie gets new glasses and sees the world in a different light. (P, M)

Heide, Florence. *Sound of Sunshine, Sound of Rain*. New York, NY: Parent's Magazine Press, 1970. Sensitive description of sounds and activities in life of a young black boy who is blind. (P, M)

Kamien, Janet. *What If You Couldn't?* A book about special needs. New York, NY: Charles Scribner's Sons, 1979. A good section on visual loss. (M, U)

Keats, Ezra Jack. *Apartment 3*. New York, NY: MacMillan Publishing Co., 1971. The story of a young man who is blind and how he makes music. (M, U)

Keller, Helen. Any books on the life of Helen Keller or Anne Sullivan.

Kent, Deborah. *Belonging*. The Dial Press, 1978. (U)

Litchfield, Ada B. *A Cane In Her Hand*. Niles, IL: Albert Whitman & Co., 1977.

Little, Jean. *From Anna*. New York, NY: Harper & Row, 1972. A little girl isn't clumsy; she can't see and needs glasses. (P, M)

McDonnell, Lois Eddy. *Stevie's Other Eyes*. New York, NY: Friendship Press, 1962. This book for younger children has a main character who is blind. (P)

Micklish, Rita. *Sugar Bee*. New York, NY: Delacarte, 1972. An urban child who is black feels uncomfortable about visiting a rural family who is white with a daughter who is blind. (M, U)

National Federation of the Blind. *Questions Kids Ask About Blindness*. 1800 Johnson St., Baltimore, MD 21230, 1980. (M)

Sargent, Susan; Wirt, Donna Aaron. *My Favorite Place*. 1983. Graceful and simple story about a little girl on an outing at the beach with her parents. (P, M)

Tannenbaum, Robin L. *A Different Way of Seeing*. Answers children's most common questions about blindness. American Foundation for the Blind, 15 West 16th Street, New York, NY 10011, 1988. (P, M)

Vance, Marguerite. *Windows for Rosemary*. New York, NY: Dutton Press, 1968. A blind girl feels so lucky to get a typewriter for her birthday. (M, U)

Wahl, Jan. *The Little Blind Goat*. Stemmer House, 1981. The little goat Casimiro cannot see but he learns to use his other senses with some help from his friends. Beautiful graphics by Attonio Frasconi. (P)

Wilder, Laura Ingalls. *By the Shores of Silver Lake*. New York, NY: Harper and Row, 1956. (M, U)

Witheridge, Elizabeth. *Dead End Bluff.* New York, NY: Atheneum Publishers, 1966. Boy who was born blind is an athlete and rescuer of his younger brother. (M)

Witte, P.E. *The Touch Me Book.* New York, NY: Golden Press, 1961. (P)

Wolf, Bernard. *Connie's New Eyes.* Philadelphia, PA: J. B. Lippincott, 1976. (P)

Woody, Regina. *Second Sight for Tommy.* Philadelphia, PA: Westminster Press, 1972. A teenager's first job is caring for a 9-year-old boy who is blind. (U)

Yolen, Jane. *The Seeing Stick.* New York, NY: Crowell, 1977. (P, M)

Books for adults

Barraga, N. C. *Visual Handicaps and Hearing.* Belmont, CA: Wadsworth, 1976.

Corn, Anne Lesley; Martinez, Iris. *When You Have a Visually Handicapped Child in Your Classroom: Suggestions for Teachers.* Practical suggestions for the regular classroom teacher whose class includes a student with a visual impairment. American Foundation for the Blind, 15 West 16th Street, New York, NY 10011, 1988.

DeMott, Richard. "The Visually Handicapped" in *Behaviors of Exceptional Children.* Columbus, OH: Charles Merrill Publishing Co., 1978.

Hanninen, K. *Teaching the Visually Handicapped.* Columbus, OH: Charles E. Merrill Publishing Co., 1975.

Jan, J. E.; Freeman, R. D.; Scott, E. P. *Visual Impairment in Children and Adolescents.* New York, NY: Grune & Stratton, 1977.

Johnson, Ysabel. *A Blind Child Becomes a Member of Your Class.* New York, NY: American Foundation of the Blind. A booklet for teachers.

Kastein, Shulamith; Spaulding, Isabelle; Scharf, Battia. *Raising the Young Blind Child.* Human Science Press, 1980. Three specialists in educating children with visual impairments discuss how parents can help their child cope with developmental milestones. Insights into emotional reactions of parents and children are included.

Krents, Harold. *To Race the Wind.* New York, NY: B. P. Putnam & Sons, 1972. An autobiography of a young man. The film "Butterflies are Free" is based on this book.

Lowenfeld, B., ed. *The Visually Handicapped Child in School.* New York, NY: John Day, 1973.

Martin, Glenda; Hoben, Mollie. *Supporting Visually Impaired Students in the Mainstream.* Minneapolis, MN: Leadership Training Institute, 1977.

Monso, Lou, et. al. *Mainstreaming Preschoolers: Children with Visual Handicaps.* Washington, DC: Dept. of Health, Education & Welfare, 1978.

National Federation of the Blind, *Questions Kids Ask About Blindness.* Baltimore, MD, 1980. Pamphlet.

Payne; Kauffman; Patton; Brown; DeMott. "Visual Impairment" in *Exceptional Children in Focus.* (2nd ed) Columbus, OH: Charles E. Merrill, 1979.

Raynar, Sherry; Drouillared, Richard. *Get a Wiggle On and Move It: Guides for Helping Visually Handicapped Grow.* Ingham Intermediate School District, 2630 W. Howell Road, Mason, MI 48854, 1975.

Scott, Eileen; Jan, J.; Freeman, Roger. *Can't Your Child See?* Baltimore, MD: University Park Press, 1977. Excellent book, designed to help parents raise a visually impaired child. Practical suggestions to help parent and child through the different stages of growth. A chapter is included on the child who is blind and has multiple disabilities.

Sullivan, Tom; Gill, Derek. *If You Could See What I Hear.* Harper & Row. 1975.

Swieringa, M. *See It My Way.* Grand Rapids, MI: The Institute for Development of Creative Child Care, 1973

Ulrich, Elizabeth, with Wolf, Ann W. M. *I Love You.* (Illustrated) Ann Arbor, MI: University of Michigan Press, 1972.

Ulrich, Sharon. *Elizabeth.* Ann Arbor, MI: University of Michigan Press, 1972. An excellent biography written by Elizabeth's mother. Early intervention ideas and comments by two experts are helpful.

Willoughby, Doris, ed. *Your School Includes a Blind Student.* Baltimore, MD: National Federation of the Blind, 1978. The book provides helpful ideas for teachers.

Willoughby, Doris, ed. *A Resource Guide for Parents & Educators of Blind Children.* Baltimore, MD: National Federation of the Blind, 1978.

Films

Films with an * are available from University Film and Video, University of Minnesota, Suite 108, 1313 -5th Street SE, Minneapolis, MN 55414; (612) 627-4270.

A School Day In The Life of A Visually Handicapped Child. (1970, black and white, sound, 24 min., #3158) Available from PA State Univ. Audio Visual Services. Order from 6 Williard Bldg., University Park, PA 10602. A story about a nine-year-old girl.

Blind Sunday. * (A.B.C. Afterschool Special Series) (1976, 31 min., color, sound, 16 mm, 7E1015) Eileen, a self-reliant high school student, accepts her blindness well. Her new friend blindfolds himself to better understand her disability. Excellent introduction for students who are sighted.

Finding My Way. * (From Zoom series, 1975, 8 min., color, sound) A boy who's blind learns independence by taking risks as he learns to get around by himself in his neighborhood. In his classroom, he uses a braille writer, a typewriter with a tactile alphabet and braille.

Happy Forward. Available from Seeing Eye, Inc., Morristown, NJ 07960. A movie about the training of a seeing eye dog and her master.

Harold. * (1978, 10 min., color, sound) A 14-year-old boy talks of his anger at becoming blind, but how he has come to understand his limitations and is enthusiastic about the future.

Helen Keller. (1969, 15 min., color, sound) Available from McGraw Hill Films, 1221 Ave. of the Americas, New York, NY 10020.

Kevin. * (1969, 16 min., color, sound, 16 mm, 4E0692) Portrait of Kevin who is blind. Useful for guidance with children and for training in special education.

Out of Left Field. (1973, 7 min., color, sound) Communities work to integrate persons with vision impairments into leisure activities. Available from the American Foundation for the Blind, 15 W. 16th Street, New York, NY 10011.

Some of Our Schoolmates Are Blind. (1960) Integration in a school in Temple City, CA. Available from the American Foundation for the Blind, 15 W. 16th Street, New York, NY 10011.

Sound of Sunshine, Sound of Rain. * (1984, 15 min., color, sound, 16mm, 5E1448) A seven-year-old boy who is blind gives us insights into his world of sounds and touch - including trips to a park, grocery store and his world of sound images.

Striving for Independence. (1968, 26 min., color, sound) Available from McDonald-Douglas Corp. Film Library, Dept. 92, Building 240, P.O. Box 516, St. Louis, MO 63166. Shows how persons who are blind overcome their disabilities and realize their ambitions.

Survival Run. * (1981, 12 min., color, sound, 16 mm, 5E1348). Blind since age 19, Harry Cordellos tackles a notorious California foot race guided only by voice and the ready arm of his partner who is sighted. Tension-building. Exhilarating finish.

The World of Deaf-Blind Children: How They Communicate. (1974, 29 min., color) Available from Campbell Films, Academy Avenue, Saxtons River, VT 05154.

The Blind: An Emerging Minority. (20 min., color) The film discusses Americans who are blind today and explains the role of the National Federation of the Blind in meeting these challenges. Available from N.F.B., Suite 715, 15 S. 5th, Minneapolis., MN 55402, (612) 332-5414.

What Do You Do When You See A Blind Person? (1971, 13 min., color, sound) Short and humorous film on "helping" a person who cannot see. Available from the American Foundation for the Blind, 15 W. 16th Street, New York, NY 10011.

Organizations

State Services for the Blind and Visually Handicapped (in each state)
1511 K Street NW
Washington, DC 20005

They provide rehabilitation services, communication services, Radio Talking Book - 24 hours a day; books (braille and taped), multimedia library on blindness, plus a store, Minnesota metro area: 642-0500; toll-free in Minnesota 1-800-652-9000.

American Brotherhood for the Blind
1800 Johnson Street
Baltimore, MD 21230
(301) 659-9319

American Council of the Blind
1010 Vermont Avenue NW, Suite 1100
Washington, DC 20005
(202) 393-3666

American Foundation for the Blind
15 West 16th Street
New York, NY 10011
(212) 620-2000 or (800) 253-4563
They publish many pamphlets - some with up to 50 copies free.

American Printing House for the Blind
1839 Frankfurt Avenue
Louisville, KY 40206
(502) 895-2405
Write for a free sample copy of the "Weekly Reader" in braille.

Association for Education and Rehabilitation of the Blind and Visually Impaired
206 North Washington Street
Suite 320
Alexandria, VA 22314
(703) 548-1884

National Association for the Visually Handicapped
22 West 21st Street
New York, NY 10010
(212) 889-3141
Produces large print books

National Braille Association
1290 University Avenue
Rochester, NY 14607
(716) 473-0900

National Federation of the Blind
1800 Johnson Street
Baltimore, MD 212306
(301) 659-9314

Perkins School for the Blind (Howe Press)
175 North Beacon Street
Watertown, MA 02172
(617) 924-3434
They have a brochure about their school.

State organizations and agencies are listed in Additional Resource Section at the end of the manual.

Hearing Impairment

What is a hearing impairment?

Hearing impairment is the term used to describe the wide range of hearing loss in persons, whether temporary or permanent, slight or profound. It is important to remember that while profound deafness is the most dramatic form of hearing impairment, the vast majority of people with hearing impairments have some usable hearing. There are many more individuals with hearing impairments that are **hard of hearing** — who can receive information by hearing alone — than there are those who are **deaf** — who must rely on visual means to receive information.

Some degree of hearing loss occurs among 15-20 million people in the United States. According to the 1989-90 Minnesota Child Count, there are 1,447 children with hearing impairments receiving special education services.

There is great variety among persons with hearing impairments. Even with similar hearing losses persons may differ enormously in intelligence, personality, interests and even in terms of their ability to speak and listen.

Hearing loss is often called an "invisible" disability. Even if a person's hearing aids are visible, his or her behavior may seem exactly like anyone else's. He or she may smile and nod appropriately and give the impression that everything is understood. Yet, the effects of hearing loss, intellectually and socially, may be enormous.

Following are some of the more frequently used terms and issues involving hearing impairments.

Degree of hearing loss

Two frequently used terms in discussing people with hearing losses are **hard of hearing** and **deaf**. Hard of hearing is generally used to describe a loss of hearing not severe enough to interfere with the use of hearing as a primary channel for learning or understanding speech with or without amplification. Deaf is used to describe a hearing loss so severe that a person is unable to understand speech through hearing alone but must also rely on a visual method or methods — like speechreading (lipreading) or manual communication.

P.L. 94-142 defines deaf as "a hearing impairment which is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification, which adversely affects educational performance." Hard of hearing means "a hearing impairment, whether permanent or fluctuating, which adversely affects a child's educational performance but which is not included under the definition of deaf above."

Unfortunately, both of these terms are frequently used imprecisely. Moreover, modern hearing aids enable many persons who would formerly have been deaf to become functionally hard of hearing. Even more important, the terms may obscure the fact that people with hearing losses can hear far better in some situations than others. A large number of individuals are hard of hearing in small quiet rooms with one or two people but effectively deaf in noisy, group situations. The term deaf is also used by many adults with impaired hearing to describe adult persons who are actually hard of hearing by measurement and who often use sign language.

Inappropriate terms used frequently by persons not well acquainted with this disability are deaf and dumb and deaf mute. The use of either term should be discouraged. Instead, just use the term hearing impaired.

Measurement of hearing loss

Hearing loss can now be measured by sophisticated equipment administered by a trained audiologist.

The hearing loss of babies and very young children can be determined with a fair degree of accuracy. Hearing loss is expressed in terms of decibels (dBs) — measuring the intensity of a pure tone of sound. A mark is made on a graph at the point where the persons can barely hear the sound at a given pitch. A loss of 20 dBs would be mild; a hearing loss of 75 dBs would be considered severe. (The criterion for noise pollution is a noise level of about 70 dBs.) Hearing can be measured up to about 110 dBs. The audiogram shows also which frequencies (Hz), which pitches of sound, can be heard and at what intensity. This is important because of the pitches of human speech.

Kinds of hearing impairment

There are two kinds of hearing impairment: **conductive hearing loss** and **nerve (sensorineural) hearing loss**.

Conductive hearing loss

A conductive hearing loss is caused by a problem in the outer or middle ear that reduces the intensity or loudness of sound. Fluid in the middle ear, damage to the eardrum, and hardening of the small bones in the middle ear are frequent causes of conductive hearing loss. Conductive hearing loss often responds to medication or surgery. If it cannot be corrected medically or surgically, a conductive hearing loss can often be overcome very successfully with the use of a hearing aid. A conductive loss may interfere greatly with the understanding of speech, but it does not cause profound deafness.

Nerve or sensorineural hearing loss

Nerve or sensorineural hearing loss is the result of damage to the auditory nerve itself which carries sound impulses to the brain. Nerve hearing loss has not been treatable, medically or surgically, in the past, but a surgical implant may provide very gross sound perception for people who are totally deaf. This is called a cochlear implant. The University of Minnesota's Department of Otolaryngology offers this important new technology to appropriate candidates. The cochlear implant is actually a system. Part of the system is implanted in the temporal bone (behind the ear), and part of it is worn externally, like a hearing aid. The implant allows users to detect and recognize many environmental sounds. It significantly aids speech understanding with lip-reading, and improves voice modulation by the user. Nerve hearing losses range from a very mild loss to the most profound deafness.

Nerve hearing loss may cause problems over and above those caused by conductive loss. Nerve loss may produce distortion of sound. A person may hear a sound, but if the sound is amplified it is so unclear or garbled that it is not recognizable. Second, because of the nature of the auditory nerve, a person with some nerve deafness frequently hears low-pitched sounds much better than high-pitched sounds. This is unfortunate since the sounds necessary to understand human speech are in the middle and upper pitches. Moreover, the sounds necessary to distinguish consonants are higher-pitched than vowel sounds; yet it is the ability to discriminate among consonant sounds that makes English speech comprehensible.

Some nerve losses may be so great that a person is unable to hear anything even with the strongest amplification available. There are significantly fewer persons with profound nerve deafness than with more moderate nerve losses. Many individuals with nerve hearing losses profit enormously from hearing aids. They are able to use their residual hearing to a great extent.

Hearing losses may be caused by hereditary tendencies. Persons with progressive hearing loss in later life as well as children born with impaired hearing may both inherit their hearing loss. Hearing loss may be caused by a trauma to the developing fetus. It may result from injury at birth. Until the invention of the vaccine against rubella, a number of babies were born deaf because their mothers had contracted German measles while they were pregnant. Deafness in children may also result from illnesses such as meningitis and, less frequently now, from red measles and scarlet fever. Some life-saving drugs also cause deafness. The cause of hearing impairments in many children, however, remains unknown.

Relation to age

The age at which hearing loss occurs is very significant. A very important distinction between individuals with hearing loss and the effect of that hearing loss on their overall development is the age at which the hearing loss occurs. If a substantial hearing loss occurs before speech and language are acquired normally, the person is said to be **prelingually deaf.** In this case the person's whole development, his or her perception and language, is dramatically affected. If a person becomes deaf after acquiring language, particularly after he or she is an adult, the effects on language and knowledge acquisition are much less severe, even though that person may be more hearing impaired than one whose hearing loss occurred at birth.

What is audiology?

The science of modern audiology, the measurement of hearing and the development of modern hearing aids, dates from the effort to rehabilitate veterans with hearing impairments after World War II. Systematic, early fitting of young children with hearing impairments with appropriate hearing aids dates only from the 1950's. Today, infants as young as a few days old may be fitted with body aids or powerful over-the-ear aids. Recent miniaturization of hearing aids has permitted many persons with severe or profound losses to wear behind the ear hearing aids; twenty years ago, these children would have all had to wear very bulky hearing aids which would have been less effective.

Modern hearing aids are marvelous helps for many individuals. They permit hard of hearing people to approach normal hearing in many situations. They enable other people, who would otherwise be deaf, to become functionally hard of hearing in some situations.

However, it is important to recognize that hearing aids have a number of limitations. They do not do for poor hearing what eyeglasses often do for poor eyesight. Hearing aids are only aids. They are unable to make a person hear perfectly.

Hearing aids are delicate and can malfunction. They depend on batteries; toward the end of a battery's life, hearing aids become less powerful. The earmold, which is custom-fitted into a person's ear, must be fitted exactly. Growing children need to have new earmolds made frequently.

There are other even more serious limitations. Hearing aids amplify all the noises in the environment as well as speech. This makes it very difficult to discriminate among speech sounds. In some cases, environmental sounds can be unpleasantly loud. A person who is hard of hearing may be delighted to hear a pin drop, but a fork dropping may sound like a loud crash. A person with a hearing aid may hear clearly in a quiet room with one or two people, but be unable to hear in a loud room with many people talking at once - like in a factory, or a school lunchroom, or a noisy bus terminal.

Secondly, hearing aids become less effective with distance. If a speaker is more than three or four feet from the hearing aid microphone, the aid begins to lose effectiveness. The FM Auditory Trainer (used in many schools and often referred to by its trade names as a "Phonic Ear," "Telex," "Oticon" or personal FM system) overcomes this problem to some degree: the speaker's voice comes in, on FM radiowaves, more clearly than environmental noises and always operates at the most desirable distance from the wearer's hearing aid. The teacher or speaker wears what looks like a microphone but is actually an FM radio transmitter; the student receives the signal on a receiver worn on the chest or belt. Newer models have neck loops.

Hearing aids, combined with speechreading and/or sign language, are invaluable for many children with hearing impairments. These children can learn some speech through hearing rather than through just visual means.

What are the means of communication?

In the United States, people who are hearing impaired use a variety of methods of communication. Traditionally, disagreement on which methods are most appropriate, or which methods should be tried first, have characterized the history of education for the deaf in this country and have divided many professionals.

Many persons whose hearing is lost or deteriorates late in life continue to rely on speech, supplemented by lip-reading. For those children who are prelingually deaf, however, or who have severe to profound hearing losses, a variety of communication techniques are used. They use whatever works best for them.

Originally, school districts tended to adopt either **oral** or **manual** educational systems. Early in this century, when this disagreement was very fierce and might be described as a schism, students who were oral were punished for using their hands for any gestures and no attempt was made to teach speech to children who were manual.

In recent years, however, there has been considerable acceptance of a **total communication** philosophy, whereby all means helpful to the student will be introduced to find which system or method works best for each child. The methods used ordinarily include speech, the use of residual hearing, sign, finger spelling, mime and acting. A system called **Cued Speech**, which relies on hand movements representing certain sounds, is also used, although much less frequently.

Sign language

Generally speaking, when we refer to sign language, we mean the use of hand gestures to represent certain concepts. However, there are different sign languages in use. The oldest method is **American Sign Language (A.S.L. or Ameslan)** which is a distinct language with its own grammar and syntax.

In addition to American Sign Language, a variety of forms of **Signed English** are frequently used in schools in an effort to teach English grammar and syntax and by parents in communicating with young children. These systems incorporate such aspects of English as articles, tenses and specific words. There are also a number of variations between A.S.L. and Signed English systems.

Finger spelling or the use of the manual alphabet is used to supplement signs representing concepts, especially for proper names and long specific terms.

Oral communication

While often now a component of total communication, oral communication is still taught separately in some school systems and to some students, particularly those with moderate hearing losses. Some programs are still strictly oral at least for younger children because of the belief on the part of some professionals that the introduction of manual methods interferes with the development of oral speech and language. Originally, oral communication meant lip-reading or speechreading, which is a very difficult skill and not necessarily related to intelligence. Even an expert lip-reader can be confused by a speaker with whiskers, with a strong foreign accent, or with very little facial or lip movement.

At present, however, oral communication is really oral/aural communication and relies heavily on the component of residual hearing which is vastly more prevalent now that powerful hearing aids are routinely fitted to most children with hearing impairments shortly after diagnosis. In addition to regular hearing aids, special FM units, where the speaker as well as the child wears a device, are now available in schools. These greatly minimize some of the disadvantages of hearing aids, like the problems with environmental noise and the problem of distance from the speaker.

What problems accompany hearing loss?

It is obvious that a hearing loss causes a person to not hear, or to misunderstand spoken language and other sounds. Another problem which is associated with a hearing loss is the feeling of isolation.

Language difficulties

The problem that people who are profoundly deaf have in speaking clearly is obvious. Less obvious, but perhaps more important, is the language problem associated with hearing impairment. Recent studies show that even temporary, conductive hearing losses in children below the age of four can cause permanent language deficits.

The most efficient time for language acquisition is from birth to four-years-old. Children with greatly reduced hearing sometimes reach the age of five or six with almost no language if they are not taught a method of sign preferred by the parents. Even with early education and the teaching of communication strategies to young children with hearing impairments, there are apt to be serious language problems. Difficulties in mastering the English language include limited vocabulary, grammatical problems, difficulties in producing or understanding long sentences, particular problems with written language and difficulties in reading comprehension. One might assume that persons who are deaf could compensate for their lack of hearing by extensive reading; in fact, the language problems that many persons who are prelingually deaf face make reading to gain information very difficult. This language deficit might place limits on educational and employment opportunities.

Language deficits also make it more difficult to understand speech. What is sometimes interpreted as an inability to hear speech or a certain sentence may really be an inability to understand the vocabulary or the idiom which is being expressed.

Early diagnosis and early educational opportunities for children with hearing impairments attempt to address these critical language problems. Total communication enables some children to develop language at a very early age. Most educational programs for children with hearing impairments focus heavily on the teaching of language.

Social isolation

If language problems and gaps in information are problems faced mainly by persons with prelingual hearing impairments, virtually all people with hearing impairments experience feelings of social isolation. A hearing loss tends to separate an individual from other people. Even persons who have enough hearing to understand perfectly in one-to-one situations may be almost totally lost in noisy groups or casual encounters. They miss almost all the small talk or chatter going on around them all the time.

This failure to understand casual, oral conversation clearly is compounded by the embarrassment many persons with hearing impairments feel at having to repeat themselves because their speech is not understood. Many become reluctant to join in on conversations for fear they may have misunderstood what is going on and thus may make an irrelevant comment.

The social isolation people with hearing impairments feel is not just the unhappiness that comes from being different or wearing hearing aids. They are truly out of it in many conversations and social gatherings. For people who can hear to genuinely include persons with hearing impairments, it is frequently necessary to make an extra effort to include them.

The preceding information on hearing impairments was provided by Barbara Flanigan, a former member of the PACER Center Board of Directors and a parent of a young adult with hearing impairments.

Lack of background information/acquisition

Another significant deficit for many people with hearing impairments is the lack of background information. Even persons who are hard of hearing have difficulty "overhearing" conversations or information. Persons with very severe hearing losses miss out on radio, TV (especially if there is a voice-over), and on casually-imparted information. Information which most people acquire almost effortlessly is simply not received. The language problems of many people who are prelingually hearing impaired make it difficult to compensate for this lack through voracious reading. What is sometimes mistaken for low intelligence or naivete on the part of persons with hearing impairments is, in fact, frequently a result of gaps in information. Many subtleties are lost or misunderstood.

What is deaf-blindness?

Occasionally, children may have a hearing impairment and a vision impairment. When this requires a special type of educational program, P.L. 94-142 regards it as a separate educational category.

Deaf-blind is defined as "concomitant hearing and visual impairments; the combination of which causes such severe communication and other developmental and educational problems that they

cannot be accommodated in special education programs solely for children who are deaf or blind."

Children who are deaf-blind are taught to communicate by using the manual alphabet spelled directly into the palm of the hand and American Sign Language.

Aids and appliances for individuals with hearing impairments

Aids and appliances commonly used by persons with hearing impairments are listed below. However, not all persons would use all of the items mentioned.

Hearing aid: An instrument that increases the volume of all sound. It may be worn on the body, behind the ear, or sometimes attached to glasses. Aids may be used for one ear or both. (See hearing aid information on page 30)

Auditory trainer: A receiver is worn by the child, while a microphone is worn by the teacher or parent. The voice of the speaker, but not the background noise, is amplified.

Phonator: A vibrating device is placed in the hand of the child so that speech sounds going into an attached microphone can be "felt" by the child.

Communication devices: Many persons with hearing impairments are increasingly taking advantage of other electronic devices which help to bridge the communication gap. Special telephones for persons with hearing impairments, TDD's (telephone devices for the deaf formerly called TTY's), enable persons to use telephones for communication of written messages to others with similar devices. There are relay services which enable people with hearing impairments to have calls made to persons who can hear with regular phones (doctors, employers, etc.). The relay operator acts as an intermediary between the caller using a TDD and the person who can hear who does not have a TDD. Finally, since March 1980, it has been possible to buy TV adapters which decode closed captions on some TV programs. The costs have decreased dramatically in recent years due to increased technology.

Feelings about being deaf

In *Feeling Free* (Reading, MA: Addison-Wesley Press, 1979) a boy and a girl who are hearing impaired describe their thoughts about being deaf and dealing with communication problems. Gordon says:

> I know that people are curious about what it's like to be deaf, and I don't mind it when they ask me all their questions. I just wish they would stick around for the answers. When I have something really important to say, I can make myself understood one way or another.
>
> My brother Chris isn't deaf, and we fool around just like any two brothers. Sometimes we like each other and sometimes . . . well, you can't like someone all the time, can you?
>
> Chris doesn't know how to use sign language as well as I do or as well as my mother does. But, when we have something to say to each other, we can usually make it happen. I have a lot of ways to make myself understood. I can use speech a little, but mostly I use sign and finger spelling. But, there are also a lot of expressions — smiles and frowns and acting things out — that can help me tell him what I'm thinking or how I'm feeling or what I want to do.
>
> When I go into a restaurant or when I'm walking somewhere with my mother, I usually notice people looking at me. Sometimes they are pointing and other times they're imitating my sign language and making fun of me. I guess people aren't used to seeing sign language, but I am confused about why they act fresh.
>
> It makes me a little angry when I see people staring at me, but I've just learned to say, 'So what? Big deal!' and go on my way. I know that I'm not going to be able to change everybody in the world.

Sometimes people even think I'm drunk. That's because they hear me trying to speak, and it sounds to them like funny words and strange sounds. Or else, someone might come up to me and say 'How are you?' but since I can't understand them, I don't say anything. So they think I'm drunk.

But people who can hear just ignore me sometimes. It's like they won't take the extra time to listen to me or to understand my questions. That makes me feel as if they just don't care at all.

When I just happen to meet up with someone new, it can be pretty frustrating. That person doesn't know that I'm deaf, and I really can't read his or her lips so neither one of us can understand the other. I'll usually find a pencil and write 'I'm deaf' and then at least the other person will know what's going on. But it's hard to carry on a conversation like that for very long, so usually I'll just say 'So long' and go on my way. It's not that I don't want to stay and talk with the other person or try to be friends, but it's just hard — hard for both of us. That's why I wish everybody knew how to use sign.

Kim, who relies on lip-reading for communication, states:

One of the hard things about learning to read other people's lips is that a lot of words look so much alike. This happens all the time with words for questions, like 'what', 'where', and 'why' — they all look the same when people speak them. Also, people sometimes speak too fast for me to understand what they're trying to tell me, so I have to keep asking them to slow down and repeat things.

A lot of times, when I'm with a group of people, it seems like everyone is talking at the same time — and very quickly — so I start to feel a little left out. I really want to know what they're all saying, and I try hard to understand. Usually, though, I'll ask one of the kids near me to help me out and it isn't a big problem.*

*Reprinted from *Feeling Free*, © 1979, American Institutes for Research by permission of Addison-Wesley Publishing Company, Inc., Reading, MA 01867. All Rights Reserved.

Puppet used to portray deafness

The puppet who depicts deafness is operated by two people. One person slips his/her hands and arms into sleeves so that actual sign language can be used. The other person operates the head and mouth movements.

Jay is the puppet who wears a body aid and has a receiver "button" in his ear. Although he is profoundly deaf, he communicates with speech and sign language and can lip-read. His speech is somewhat difficult to understand. The puppeteer places his/her tongue on the lower teeth and flattens the voice sound to simulate that of a person who is hearing impaired.

Questions our puppet has been asked

Do you always wear your hearing aid?

Oh yes, whenever I'm awake. But, I don't wear it when I swim, take a bath, or sleep. Sometimes when I'm in a room that's very noisy, I turn it off because the sounds get so loud and garbled.

Can you play outside even though you can't hear what's going on?

Sure, I just have to WATCH out for things—like frisbees, baseballs, and cars. Some things I can feel—like thunder, or a heavy truck rumbling down the road. I'm very careful when I cross the street—I look very carefully both ways.

Can you hear sounds in your house?

Some sounds—even some speech—I can hear, but I have to listen very hard. Some sounds I can feel—like the stereo. If it's very loud, I can also hear it—or the radio—even the vacuum cleaner. If Mom wants my attention, she stamps twice on our wooden floors, and I turn around. But, I can't hear the doorbell or telephone. We have the doorbell wired to make a light flash on and off, so you know someone is at the door.

Can you use a telephone?

If the light for our phone flashes, I just pick up the phone and say, "Hello, wait a minute please." Then I go get someone, usually one of my sisters (the phone is usually for one of them anyway), and then they pick up the phone and find out who it's really for. So no, I can't hear on a regular phone, but . . .

When I'm 10, Mom and Dad said I can have a TDD (telephone device for the deaf)—that's a special telephone-typewriter for persons like me. Then I can call and type to any of my friends who have a TDD, too.

How did you learn sign language?

Just like you learned speech. My family and teachers (I started having teachers come to my house when I was just a year old) would name everything I saw or wanted and use signs all the time, and I learned to sign.

How could you learn speech if you can't hear your voice?

My family always talks to me, too, and sometimes I catch a bit of sound from my Dad's deep voice. But it's really hard. My speech teacher and I have worked a long time and I would sit in front of a mirror to see the shape of my mouth. I also would feel my throat and nose to feel vibrations.

On TV, what does "closed captioned for the hearing impaired" mean?

Captions are printed words at the bottom of a TV screen to give information or to explain what is going on. You've probably seen captions for weather bulletins at some time. Well, closed captions show only on TV screens of people who buy "decoders" for their TV. People who are hearing impaired like TV decoders, so they can fully understand the programs through the captions.

Do your ears hurt?

No. Being deaf isn't painful. It's just that my ears don't get the sound waves to my brain like yours do.

Simulation activities for hearing impairments

1. **"SILENT MOVIE"**

EQUIPMENT: A cartoon or short film unfamiliar to class.

For elementary students: Run the film in its entirety without sound. Let the class discuss what they thought went on, or have them write their ideas on what happened or what was said in the film. Then rerun the film and have children compare their notes with what actually happened. Discuss their feelings about not being able to hear.

For preschoolers: If the class has a TV, turn sound off for one minute of Sesame Street and see if they can tell what is going on.

2. **"SILENT TIME" or "SILENT MEAL"**

EQUIPMENT: None

Designate a portion of the day (such as one hour) when no one can talk. To get something, they have to gesture. To understand, they have to read lips. To express a thought, they may have to act out or dramatize. (Do not allow students to

communicate by writing notes — that's too easy.) Discuss which things were easy to communicate and which were difficult.

3. **RECORDS THAT SIMULATE SOUNDS AS HEARD BY PEOPLE WHO ARE HEARING IMPAIRED**

"HOW THEY HEAR: The Sounds of Abnormal Hearing" (Written and narrated by Earl Harford, Ph.D., produced by Stowe and Associates) simulates several types of abnormal hearing.

Check with your school or district librarian, or special education resource center to learn if the record is available.

4. **"CATCH THE WORDS"**

EQUIPMENT: Chalk and eraser for leader or teacher, paper and pencils for the children.

The leaders, without talking, should write a word or sentence on the board, erasing each letter as soon as it is written. The students must write the same word or sentence on their papers. Have them discuss how complete the word or sentence is on their papers and the difficulties they may have felt in trying to catch by sight everything that was printed. Repeat the activity, this time with the leader saying aloud each letter or word as it is printed. Does "hearing" make the activity easier?

5. **"PANTOMIME"**

EQUIPMENT: None

Discuss how signs are used in many instances to give information: traffic cops, sports umpires, airline personnel. Have each child convey some action or information without using words: brushing teeth, putting on a coat, pouring a glass of milk, etc. Act out a familiar story.

6. **"SOUNDTRACK"**

EQUIPMENT: Tape recorder and cassette tape

Tape record a conversation with a friend in a noisy place (e.g., outside, to pick up cars, planes or at a party with music, others talking). Have someone listen to the conversation and tell you what is being said. Hearing aids, like the tape, amplify all sounds. See how hard it is to separate all the sounds. Now you might know how frustrating it is to be hearing impaired.

Resources

Hearing aid information for teachers and parents

The different types of hearing aids - The purpose of any hearing aid is to amplify and reproduce sound in order to enhance a person's hearing. Amplified sound is louder than unaided sound; a sound occurring 10 feet away may seem like it is four feet away when heard through a hearing aid. The major visible differences between hearing aids are the size and the place where they are worn. Larger aids must be worn on the chest and are referred to as body-type aids or the conventional hearing aid. These aids are held in place by a pocket or strap-like harness which is worn over or under the individual's clothing. A wire of varying length (two feet to three feet) connects the body aid to a receiver and an earmold which fits into the ear. Due to modern technology, body aids can now be reduced to the size of a credit card.

Smaller aids are worn on the head, specifically, behind the ear (BTE), in the ear, or on a pair of eyeglasses. A person may wear one aid or two aids. Most children wear BTE aids as opposed to in the ear (ITE) or eyeglass hearing aids.

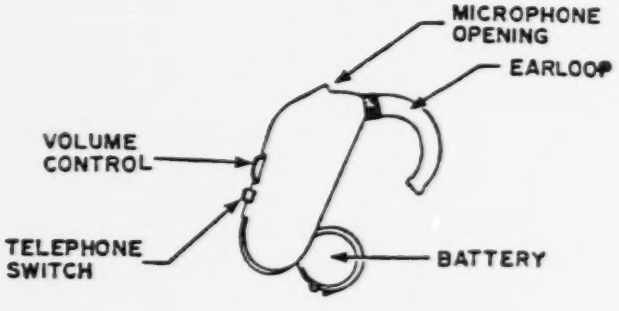
The type of aid that a child wears should be determined by an audiologist. This person is qualified to evaluate hearing impairment and make recommendations for habilitating the hearing loss which may include wearing a hearing aid(s). There is a federal law (801.420) and a Minnesota State Statute

which stipulate procedures for the sale of hearing aids. Both of these laws stipulate that a person with a hearing loss must have a medical evaluation by a licensed physician before purchasing an aid. In addition, children with a hearing loss should be directed to an audiologist. NO hearing aid dealer may sell a hearing aid to a person without a doctor's prescription. A waiver to this ruling can be signed by persons over 18 years of age and under 60 years (this age specification was established in the state law), if the dealer reads the specific requirements in the Federal Register of February 15, 1977, to that person. Therefore, no child should ever be wearing a hearing aid that has not been specifically recommended by an audiologist and a physician.

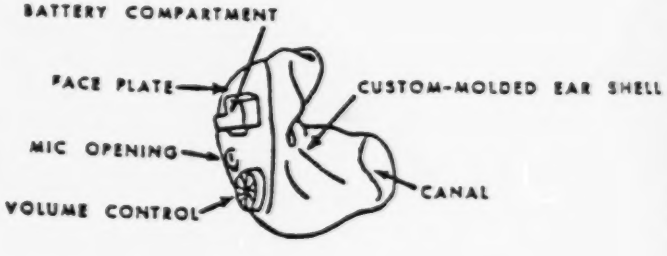
The following sheet will provide valuable information on the parts of hearing aids. These diagrams should help one visualize what an aid looks like. This is the first step in getting acquainted with the instrument that you may be responsible for maintaining.

Written by Christine Painter, Audiologist

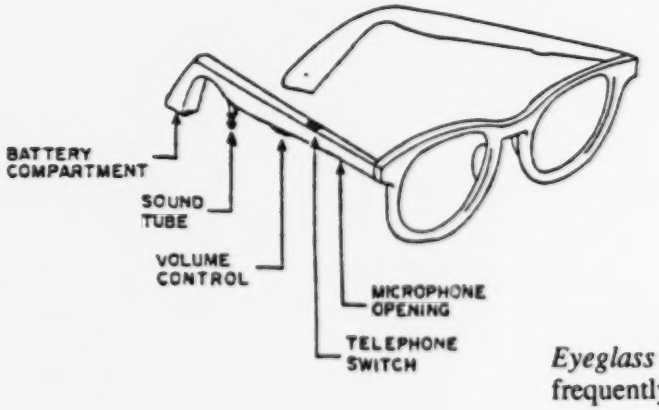
Parts of the Hearing Aid



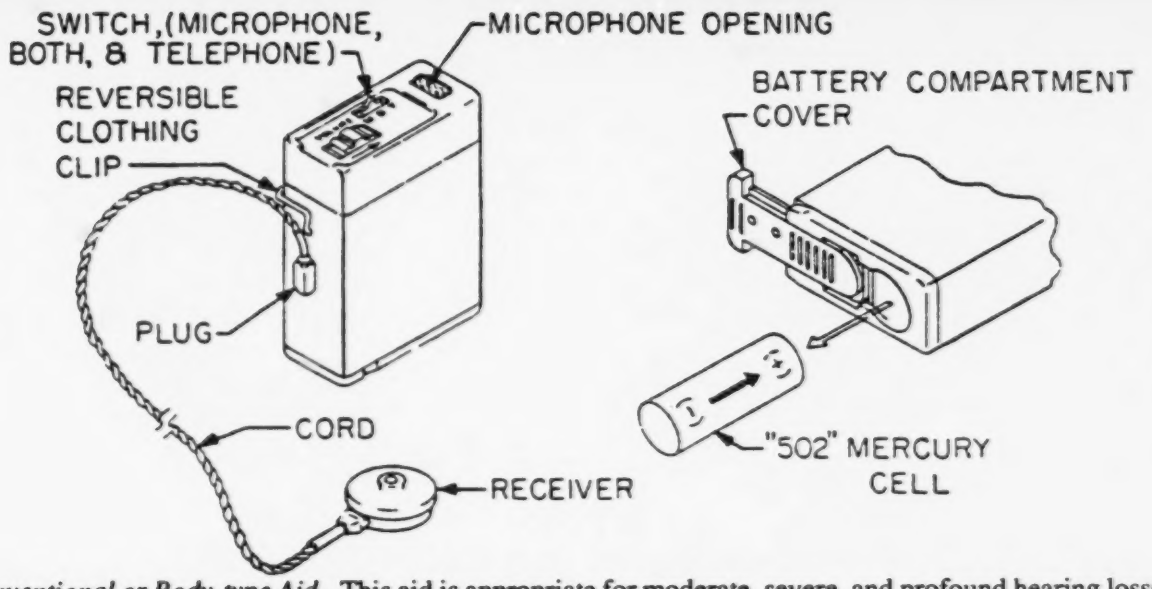
Behind The Ear Aid (BTE) - This aid is appropriate for a wide range of hearing losses.



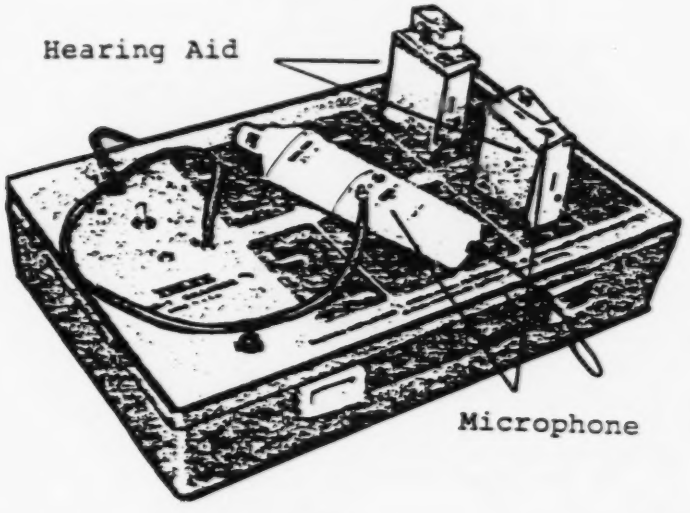
Custom-molded In The Ear (ITE) - is appropriate only for mild and moderate hearing loss.



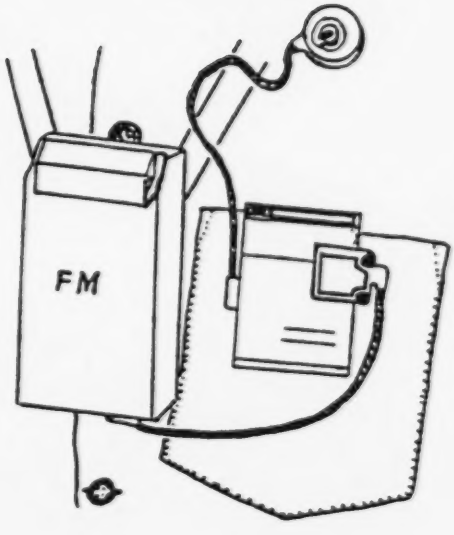
Eyeglass Hearing Aid - This aid is most frequently worn by older adults.



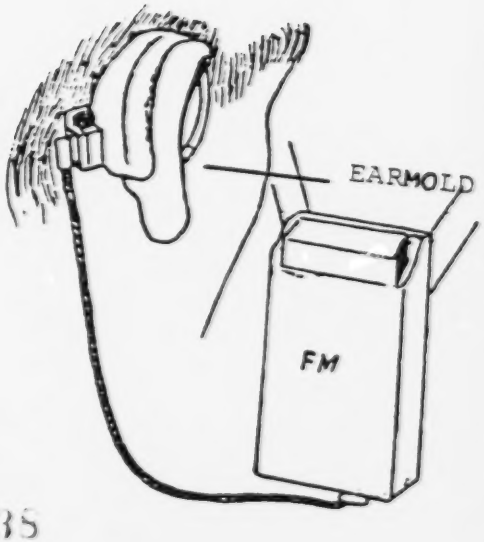
Conventional or Body-type Aid - This aid is appropriate for moderate, severe, and profound hearing losses. This aid is usually worn at chest level.



Example of an *FM Auditory Training System* - This system has three essential parts: a microphone worn by the teacher or other speaker, body-type aids that are adjusted for each child's particular hearing loss, and a box or tray which holds the aids and microphones as well as charges them over night.



An *FM Auditory Training System* may be used with a child's personal behind-the-ear aid or body-type aid.



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Earmold - The earmold is a separate piece on all types of aids except the in-the-ear aid. It attaches to the earloop of the behind-the-ear aid, the receiver of the body aid, and may attach to the sound tube of the eyeglass aid.

Who maintains the hearing aid?

Most children with hearing impairments will utilize some form of amplification. It is essential that the hearing aid is working optimally during school hours. Younger children will not always be able to monitor and check the functioning of their aid.

Part of the new federal law, P.L. 94-142, states that the school district shall insure that hearing aids are functioning properly. A hearing aid is not a complicated instrument. Learning how to care for a hearing aid does not require one to know how it works mechanically. In addition, the maintenance of a hearing aid should not be the sole responsibility of the classroom teacher. Therefore, the classroom teacher should know the following:

1. Who is the resource person in the district responsible for maintaining records and any additional equipment being utilized for the child with a hearing impairment: teacher of people with hearing impairments, principal, special education director?

2. The parts of a hearing aid and also the different types of hearing aids commonly worn by children.

3. The manner of checking a hearing aid by listening to the instrument and by observing the auditory behavior of the child.

It is possible that there will be no staff person within the school building who knows about hearing aids other than the classroom teacher. However, there will be someone within the school district who was initially responsible for ordering an auditory training system and thus should be familiar with the maintenance necessary to keep the aids functioning properly. Any team member who has direct contact with the child, e.g., speech pathologist, hearing impaired specialist, or parent, shares the responsibility of maintaining the hearing aid. These people are valuable resources for gaining information about hearing aids and hearing impairment.

Here is a list of some general "do's and don'ts" about any hearing aid:

1. Do not get the hearing aid wet, e.g., a body aid would need a plastic cover for water play activities.

2. Always turn the aid off when it is not being worn.

3. Do not take the aid apart and attempt to repair it.

4. Do not place the aid in extremely hot or cold places, e.g., do not place an unworn aid on a heater.

Listening checks for a hearing aid:

A listening check of a hearing aid should be done whenever a teacher suspects that a hearing aid does not work. This implies that the teacher can "see" that the child cannot "hear." There are, therefore, a few things that a teacher should know about the individual child with hearing impairments.

1. Does the child know how to put on his/her aid?

2. Does the child know when the aid is off or on?

3. Does the child follow directions without looking at you?

4. Does the child know how to change the battery in her/his aid?

5. Does the school have spare batteries for the child's aid?

If the answers to the above questions are "yes," then it will be easier to spot an aid that is not functioning properly; it is likely that the child will tell you that his/her aid is dead or not working. It is important that the teacher know what is normal listening behavior for the child. If the child seems unusually inattentive or unusually moody, it would be advisable to make a listening check with the hearing aid.

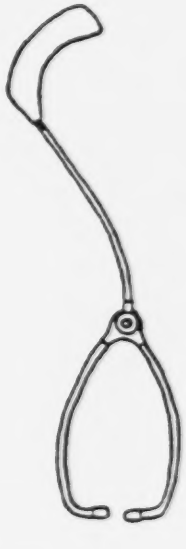
Listening check with a conventional hearing aid:

1. Place the earmold and receiver in your ear or use a stethoscope listening set. This piece can be purchased by the school district from a hearing aid dealer for approximately $12.00. If you are listening with only the earmold and receiver, put your hand over your ear and hold the main part of the aid away from you ear to prevent feedback. Feedback is the squealing or whistling sound that is heard when an aid is on but the mold is not in the ear.

2. Turn the aid on slowly and move the volume control wheel up slowly. Listen for:
   a. A significant uniform increase in the sound of your voice and/or the sounds around you.
   b. Clarity in the amplified sound as you speak into the microphone, i.e., say the sounds ba-ba-ba and count to ten.

3. The following "sounds" indicate that the aid may need repair by a dealer.
   a. Fuzziness in the sound of words, particularly the numbers seven and six.
   b. Squealing sound in the aid when you have it sufficiently held to your ear; most often a squealing aid is indicative of an improperly fit earmold. However, if the squealing or whistling persists even with your finger held over the hole at the end of the earmold then the aid may need servicing.
   c. Absence of sound is usually indicative of a dead battery. If using a fresh battery produces no amplified sound, the aid should be sent home with instructions for repair and/or an additional opinion by an audiologist.

Stethoscope Listening Piece



Listening check with an auditory training system:

The checks made with this system are quite similar to that of the conventional body aid except for one difference—this system necessitates checking two microphones (see parts of a hearing aid).

The hearing aid portion of this system will have switches that indicate which of the microphones is being utilized.

M - hearing aid microphone
T - microphone held by teacher
B - both microphones are activated

The letters on the unit may be different from the example above. It is important that you know on which switch the hearing aid is operating.

Check the "M" Switch: Listen exactly as you would with a conventional body aid.

Check the "T" Switch: Talk into the hand held microphone and follow procedures of conventional check.

Check the "B" Switch: Talk into each microphone separately and be sure they are amplifying sound. Listen in the same manner described for conventional aids.

This type of equipment must be recharged daily and must, therefore, be turned on at the end of the school day. In some cases, the individual child for whom this equipment was purchased can be taught to be responsible for turning on the equipment before leaving school. If this equipment is owned by the school, it is their responsibility to have it repaired if it "fails" the listening check. It is important that the classroom teacher know the procedure for reporting faulty equipment in that particular school building.

Listening check with an ear level aid:

This check is sometimes difficult because the incidence of feedback is increased by the proximity of the microphone to the sound opening of the earmold. Therefore, it is strongly suggested that a stethoscope listening set be utilized (see page 39). Using a stethoscope, the listening check would proceed the same as with a conventional aid. If there is not a stethoscope available, then the listening check will have to be done by placing the earmold into your ear and placing your hand or finger over the mold to insure a tight seal. Sometimes the child's earmold will fit the listener's ear securely enough for an accurate check.

However, remember that if the earmold does not fit tightly, there will be feedback; this feedback or squealing will not be indicative of a malfunctioning hearing aid.

Care of the earmold:

Some children who wear hearing aids will maintain the earmold by washing it appropriately at home. If this is not done, then the classroom teacher could check for wax accumulation in the earmold canal tip. A plugged opening will reduce the amplification of the aid significantly, and the child may act as though s/he does not hear. A plugged earmold may also produce a squealing feedback sound. If the opening is plugged, simply remove the wax with a toothpick, pin, or pipe cleaner. If the earmold appears to be grossly impacted with wax, remove the earmold piece form the hearing aid and wash it with a mild soap and water solution. Blow out the water before placing the mold back on the hearing aid. It is recommended that you do not use alcohol for cleaning as it may harden the mold over time and become uncomfortable to wear.

Tips for talking with the individual who is hearing impaired*

Facial expressions, gestures and lip and body movements are all visual cues used by the individual who is hearing impaired to enhance his or her understanding. Visual cues, used together with the auditory signal, act to further improve understanding. Therefore, every effort should be made to enhance the visual cues available to the person who is hearing impaired. For example:

1. Avoid chewing, eating, smoking or covering your mouth with your hands when speaking to an individual who is hearing impaired.

2. Do not exaggerate sounds or elaborately mouth words when speaking. This distorts the message and makes the use of facial cues difficult to interpret.

3. Arrange the environment so that your own face and body can be easily seen by the person who is hearing impaired.

4. Good lighting is essential for the most optimal use of visual cues. For example, light should be shining on the speaker's face and not in the eyes of the person who is hearing impaired.

5. Face the person who is hearing impaired directly and at the same level when speaking with them.

6. The greater the distance between a person who is hearing impaired and the speaker, the softer the sound and the more difficult it is to utilize visual cues effectively. The most optimal speaker/listener distance is from three to six feet.

Environmental noise can have an extremely detrimental effect on the ability of a person who is hearing impaired to understand speech. Therefore, one should arrange the environment so that the individual who is hearing impaired is away from any noise source.

1. Avoid speaking too rapidly. The speaker should slow down and pause between sentences and/or phrases. Also, wait to make sure you have been understood.

2. Never speak directly into a person's ear. This may further distort your message and hide all visual cues. Sentences spoken a bit more slowly are much clearer than those which are shouted.

3. If the person who is hearing impaired does not appear to understand what is being said, **rephrase** the statement with different words using short and simple sentences.

4. Whenever possible, give the individual who is hearing impaired a clue as to the topic of conversation. Sudden changes in topic can be extremely confusing to an individual with a hearing loss.

5. Recognize that everyone, especially the person who is hearing impaired, does not hear as well when he or she is tired or ill.

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This material was reviewed and updated by Linda Berman, a member of PACER's Board of Directors and a parent of a child who has hearing impairments; and Harvey Hoffman, Courage Center, coordinator of programs for Persons with hearing impairments.

Resources

Books for children

(P = Primary, M = Middle, U = Upper grade level recommendations)

Arthur, Catherine. *My Sister's Silent World.* Chicago, Children's Press, 1979. A young girl describes the world of her eight-year-old sister who is deaf.

Aseltine, Lorraine; Mueller, Evelyn. *I'm Deaf and It's Okay.* Miles, IL: Albert Whitman, 1986. When a young boy who is deaf realizes that he will always have to wear hearing aids, he rebels.

Baker, Margaret J. *The Sand Bird.* New York, NY: Thomas Nelson, 1973. A child who is deaf and two friends buy a mysterious bird that changes their lives. (P, M)

Bowe, F.; Sternberg, M. *I'm Deaf Too: 12 Deaf Americans.* National Association of the Deaf: Silver Spring, MD: 1973. Contains interviews with 12 prominent persons who are deaf. (M, U)

Bove, Linda. *Sesame Street Sign Language ABC*. New York: Random House, 1985. Large, clear print with colorful, lively illustrations and photographs.

Charlip, Remy; Ancona, Mary Beth; Ancona, George. *Handtalk: An A. B. C. of Finger Spelling Sign Language*. New York, NY: MacMillan, 1986. Four Winds Press, 1974. Introduction to two kinds of sign language. Members of the National Theater of the Deaf scamper through the alphabet. (P)

Corbett, Scott. *Deaf Before Docking*. Boston, MA: G.K. Hall, 1972. A mystery story involving a boy who is deaf that reads lips. (P, M)

Davidson, Margaret. *Helen Keller*. New York, NY: Scholastic Book Services, 1969. The story of the famous woman who was deaf and blind.

Glazzard, Margaret H. *Meet Camille and Danille, They Are Special Persons*. Lawrence, KS: H and H Enterprises, 1978. The girls are identical twins who are deaf. They are mainstreamed into a class. The book gives good descriptions of the adaptations that the teacher and other children make and the difficulties of speech training and lip-reading. (P)

Hlibok, Bruce. *Silent Dancer*. Messner, 1981. The experiences of a real ten-year-old girl who is deaf and studying ballet. (P, M)

Hunter, Edith. *Child of the Silent Night*. New York, NY: Dell, 1971. An inspiring story of a girl who is deaf and blind. (P, M, U)

Levine, Edna. *Lisa and Her Soundless World*. New York, NY: Human Sciences Press, 1974. A little girl with profoundly impaired hearing learns to use and understand speech. (P, M)

Litchfield, Ada. *A Button in Her Ear*. Chicago, IL: Albert Whitman Co., 1976. A little girl relates how her hearing deficiency is detected and corrected with the use of a hearing aid. (P)

Multiple authors. *Helen Keller*. Any books on Helen Keller or Anne Sullivan.

Peters, Diana. *Claire and Emma*. New York, NY: John Day, 1977. Claire is four and her sister Emma is two; both were born deaf. Bright, color photos show them engaged in many activities. Information about speech training, lip-reading and hearing aids given. Excellent. (P)

Peterson, Jeanne Whitehouse. *I Have a Sister, My Sister is Deaf*. New York, NY: Harper and Row, 1977. A warm, mutually supportive relationship between two sisters makes this a sensitive book depicting an exceptional child in the family. (P, M)

Robinson, Veronica. *David in Silence*. Philadelphia, PA: J.B. Lippincott, 1965. In the new town where his family has moved, David, who has been deaf since birth, finds himself disliked by the other children. (M, U)

Seines. *Sign Language Animals*. An educational coloring book for elementary and pre-school children. (P)

Star, Robin Rogoff. *We Can!* Volumes 1 and 2. Alexander Graham Bell 1980 Career Education Series presents stories of people who are hearing impaired leading full and independent lives. (P, M)

Sullivan, Mary Beth; Burke, Linda. *A Show of Hands, Say It In Sign Language*. Reading, MA: Addison-Wesley, 1980. Large cartoon-like drawings illustrate sign language and finger spelling. (P)

Wolf, Bernard. *Anna's Silent World*. Philadelphia, PA: J.B. Lippincott, 1977. Anna was born with a profound hearing loss, but leads an active life. (M, U)

Zelonky, Joy. *I Can't Always Hear You*. Milwaukee, WI: Raintree, 1980. Kim, a girl of about 10 who uses a hearing aid, tells how she learned to adjust to a mainstreamed classroom and struggled with the way others treated her.

Books for adults

Hard of hearing — These two books deal with the problems of children who are hard of hearing, in contrast to many books in this field which are largely concerned with children who are severely or profoundly deaf .

Berg, Frederick S.; Fletcher, Samuel G., eds. *The Hard of Hearing Child.* New York, NY: Grune and Stratton, 1970.

Davis, Julia, ed. *Our Forgotten Children: Hard-of-Hearing Pupils in the Schools.* 1977.

Deafness

Altman, Ellyn. *Talk With Me.* Alexander Graham Bell Press, Assoc. for the Deaf, 1988. The ins and outs of raising a child who is hearing impaired. The mother is a clinical psychologist.

Asley, Jack. *Journey Into Silence.* 1973. Account of experiences and coping techniques of a British member of parliament who became deaf.

Benderly, Beryl Lieff. *Dancing Without Music, Deafness in America.* Anchor/Doubleday, 1980. This book provides a discussion of deafness in America including a complete discussion of the issues in the oral vs. manualist controversy.

Birch, Jack W. *Hearing Impaired Pupils in the Mainstream.* 1975. Discussion of when to mainstream and how to mainstream children with hearing impairments effectively.

Bitter, Grant B., ed. *Parents in Action: A Handbook of Experiences With Their Hearing Impaired Children.* Washington, DC: Alexander Graham Bell Assoc., 1978. Thirteen parents of children with hearing impairments write frankly of their experiences.

Freeman, Roger D.; Carbin, Clifton F.; Boese, Robert J. *Can't Your Child Hear? A Guide for Those Who Care About Deaf Children.* International Association of Parents of the Deaf. Baltimore, MD: University Park Press, 1980. This book is intended to provide a comprehensive guide for parents of children who are deaf from a total communication view point. It is written by two physicians and a psychologist from the University of British Columbia.

Glick, F.P.; Pellman, Donald. *Breaking Silence.* Herald, 1982. A mother writes of the growing concerns about behaviors of twin sons, the misdiagnosis of aphasia, professional, family and school relationships, and religion. The twins, now young men, share their views of deafness.

Harris, George A. *Broken Ears, Wounded Hearts.* A father writes of his child, born deaf but not definitively diagnosed, with honesty and anger, as he outlines his frustrations in dealing with the child and the professionals who see and work with her.

Harris, Rosemary. *The Bright and Morning Star.* New York, NY: MacMillan, 1972. A novel set in ancient Egypt about a young boy who loses his hearing as a result of a fever.

Jacobs, Leo M. *A Deaf Adult Speaks Out.* 1974. Discussion of deafness by a successful adult who is non-oral deaf. Includes discussion by persons who are deaf and hard of hearing on what deafness means to them and articles by persons who are deaf of the obstacles that deafness presents in everyday living.

Kisor, Henry. *What's That Pig Outdoors?* Hill and Wang Publishing, 1990. Autobiography of a highly successful professional who is the book editor of the Chicago Sun Times. He is oral but does not get into a debate.

Lane and Pittle. *A Handful of Stories - 37 Stories by Deaf Storytellers.*

McArthur, Shirley Hanawalt. *Raising Your Hearing-Impaired Child: A Guideline for Parents.* Alexander Graham Bell, 1982. With the empathy of a parent, the author traces steps in raising a child with a hearing impairment from first learning about hearing loss to developing communication skills to guiding a child to adulthood. The book is filled with practical ideas based on experience.

Moffat, Samuel. *Helping the Child Who Cannot Hear*. Public Affairs Pamphlet No. 479, June, 1972, 381 Park Avenue S., New York, NY 10016. Excellent simple discussion of problems and educational choices for parents of children with hearing impairments.

Moores, Donald. *Educating Deaf Children - Psychology, Principles and Practices*. Boston, MA: Houghton-Mifflin, 1978.

Myklebust, Helmer R. *Your Deaf Child: A Guide for Parents*. Springfield, IL: Charles C. Thomas.

Naiman, Doris W.; Schein, Jerome D. *For Parents of Deaf Children*. Silver Spring, MD: International Association of Parents of the Deaf, 1978. Guide for parents of children who are deaf.

Neyhus, Arthur I.; Austin, Gary F., eds. *Deafness and Adolescence*. Washington, DC: Alexander Graham Bell Association, 1978. Discussion of various problems encountered by adolescents who are deaf and how to deal with them.

Nix, Gary W., ed. *Mainstream Education for Hearing Impaired Children and Youth*. 1976. Excellent collection of different aspects of mainstreaming.

Nix, Gary W., ed. *The Rights of Hearing Impaired Children*. Washington, DC: Alexander Graham Bell Association for the Deaf, 1977. Discussion of educational rights of children with hearing impairments under P.L. 94-142.

Northcott, Winifred H., ed. *The Hearing Impaired Child in a Regular Classroom, Preschool, Elementary and Secondary Years. A Guide for the Classroom Teacher/Administrator*. 1973. Many practical suggestions for teachers, a wealth of information on mainstreaming.

Oberkotter, Mildred. *The Possible Dream*. Ideas from parents of children who are hearing impaired, and the students who as a group favor the use of oral/auditory methods and mainstream settings.

Odgen and Lipsett. *Silent Garden*. St. Martin's Press, 1982. Provides useful information to parents of children with newly-diagnosed hearing impairments. Information on various modes of communication.

Padden and Humphries. *Deaf In America*. Howard University Press, 1988. A look at the culture of hearing impaired persons written by two professionals who are hearing impaired.

Pollack, Doreen. *Educational Audiology for the Limited Hearing Infant*. 1970. Very complete explanation and argument for "acoupedic" method to maximize residual hearing in infants and small children. Includes diaries of mothers of children with hearing impairments recording their frustrations and successes.

Sacks, Oliver. *Seeing Voices*. A leading neurologist/author gives his observations on deafness, the culture of the hearing-impaired and the modes of communication.

Schlesinger, Hilde S.; Meadow, Kathryn P. *Sound and Sign, Childhood Deafness and Mental Health*. 1972. Excellent study of the implications of deafness on children's social and emotional development by a psychiatrist who has worked extensively with deaf children and teachers of the deaf.

Spradley, Thomas; Spradley, James. *Deaf Like Me*. Gallaudet College Press. 1985. A family's evolution from an oral approach to one of total communication with their child who is deaf.

Stern, Virginia. *Never Too Young*. Lexington Parent Series, Lexington School for the Deaf. New York, NY, 1975. Empowering parents of children with hearing impairments to use their home as the best learning environment and learn listening and talking skills.

Vaughan, Pat, ed. *Learning to Listen: A Book By Mothers for Mothers of Hearing Impaired Children*. (rev. ed.) Beaufort, 1981. Canadian Hearing Society sponsored book which describes the process of auditory training for children. Practical suggestions for mothers and teachers.

West, Paul. *Words for a Deaf Daughter.* NY: Harper and Row, 1970. This poet and novelist writes a letter to his daughter with multiple disabilities.

Winefield, Richard. *Never the Twain Shall Meet.* Gallaudet University Press. 1987. Historical summary of the two main approaches to deafness and their legacies.

Wright, David. *The Deaf Child in the Public Schools: A Handbook for Parents.* Silver Spring, MD: National Association for the Deaf, 1978.

Wright, David. *Deafness.* New York, NY: Stein and Day, 1969. Moving autobiography of adult who is deaf and historical discussion of education of the deaf.

Magazines for adults

Shhh (ISSN 0883-1688) is published bimonthly by Self-Help for Hard of Hearing People, Inc. SHHH, 7800 Wisconsin Avenue, Bethesda, MD 20814. Telephone: (301) 657-2248 (Voice), (301) 657-2249 (TDD).

Films

Films with an * are available from University Film and Video, Suite 108, 1313-5th Street SE, Minneapolis, MN 55414, (612) 627-4270.

Lifeline to the World of Sound. (13 min., color, sound, #2639 free) Available from Modern Talking Pictures, 1212 Avenue of the Americas, New York, NY 10036. The film describes the problems of deafness and how a hearing aid helps.

Listen. (No details) Available from Total Communication Library, Western Maryland College, Westminster, MD, 1972. The film helps persons who are not disabled better understand those who have hearing impairments.

The Silent World of Jim. Available from Informational Materials, Inc., Burbank, CA. It is a story of a boy who is deaf learning about safety.

Can You Hear Me? (30 min., color, sound, free) Available from 3M Company, Film Lending Service, #220-6W, 2501 Hudson Rd., St. Paul, MN 55119. Produced in 1967. The film tells the story of the family of a 2-1/2 year old girl who is deaf and how they deal with the problems of her disability.

Helping My Parents. * (from Special Children-ZOOM Series) (6 min., color, 1978.) Young Alberta talks about growing up with deaf parents.

Mary. * (from People You'd Like to Know Series) (10 min., color, sound, 16mm, 1978, 3E1187) About an 11-year-old girl who was born deaf and talks about her feelings.

Messages By Hand. * (from Special Children-ZOOM Series) (8 min., color, sound, 16mm, 1976, 3E115) Roland Gramfors is deaf. He signs (while a narrator translates the signs for us) and invites children to learn sign language to communicate better with children who are deaf and feel isolated from others.

See What I Say. * (24 min., color, sound, 16mm, 1981, 7F1256) Feminist folk singer, Holly Near, performs in concert accompanied by mime and dance performances in American Sign Language.

What's Say? * (from Fat Albert and the Cosby Kids Series) (14 min., color, sound, 16mm, 1977, 5E1146) Shana, the new girl in town is not stuck-up and dumb, she's hearing impaired. An accident and new hearing aid help her discover a new world and a lot of friends.

Organizations

National organizations:

Alexander Graham Bell Association
3417 Volta Place N.W.
Washington, DC 20007 (They have pamphlets and other resources available.)
(202) 337-5220

American Society for Deaf Children
814 Thayer Avenue
Silver Spring, MD 20910
(301) 585-5400

Better Hearing Institute
Hearing Helpline
PO Box 1840
Washington, DC 20013
Toll free phone: (800) 424-8576

Gallaudet College
(Liberal Arts College for the Deaf)
Materials Specialist
7th and Florida Avenue NE
Washington, DC 20002
(They have pamphlets, book lists, materials and a resource catalog available.)
Toll-free: (800) 672-6720, ext. 5176 (Voice or TDD)

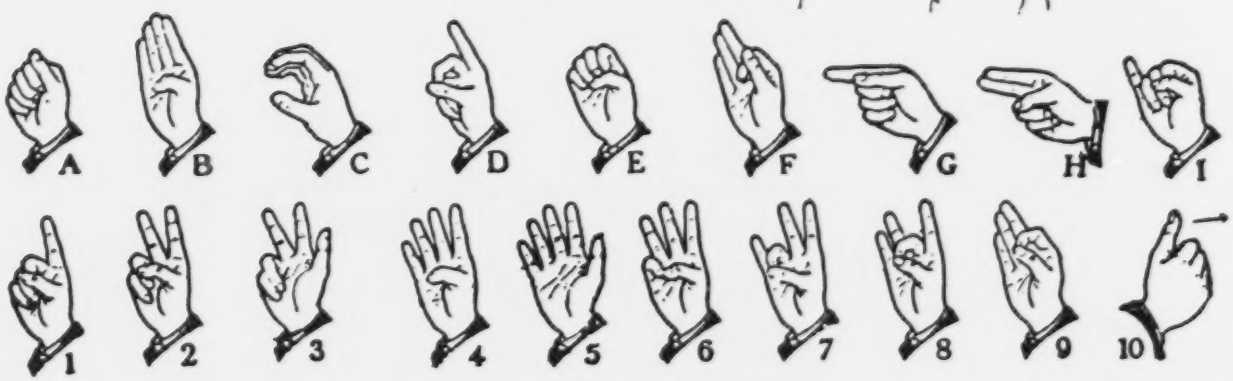
National Association of the Deaf
814 Thayer Avenue
Silver Spring, MD 20910
(301) 587-1788, Voice/TDD

National Center for Law and the Deaf
800 Florida Avenue NE
Washington, DC 20002
(202) 651-5454

National Registry of Interpreters for the Deaf
Gallaudet College
Kendall Green
Washington, DC 20002

National Hearing Aid Society
20361 Middle Belt Road
Livonia, MI 48152
Toll-free phone: (800) 521-5247 (They provide information about hearing aids and hearing loss)

State organizations and agencies are listed in Additional Resources Section at the end of the manual.



Speech Impairments

What is a speech disorder?

The disability category that P. L. 94-142 calls "speech impaired" is quite broad. A speech disorder may be part of another disability involving a known biological cause (e.g., hearing loss or cerebral palsy); speech impairment may be the only disability; or sometimes it might be one aspect of a specific learning disability. Many speech and language disorders have no known biological cause and are termed functional disorders.

P.L. 94-142 defines **speech impaired** as "a communication disorder such as stuttering, impaired articulation, a language impairment, or a voice impairment which adversely affects a child's educational performance."

Children who have speech problems represent the second largest group of children receiving special education services in elementary schools in America. In Minnesota, 16,606 children received speech service in 1989-90.

Many young children have some speech differences from their peers. Often these differences do not adversely affect the child's educational performance. When they do seem to be interfering with learning progress, that child's development should be assessed by a professional.

Communication disorders can be characterized by problems in any one or a combination of the following:

Articulation or phonological disorders are problems related to the sounds in a language. Errors might be omissions, substitutions, or distortions of sounds.

Voice disorders are usually identified as significant deviations in pitch, loudness or tonal quality. A child with persistent hoarseness should be seen by a physician and by a speech/language pathologist. Nasality and denasality are usually the result of muscular or structural problems and often require medical services in addition to speech therapy.

Language disorders include a wide range of problems relating to a child's understanding of what others say (receptive disorders) or to his or her ability to express ideas in words and sentences (expressive disorders). Children who have difficulty understanding language usually but not always have difficulty expressing themselves. The reverse is less often true.

Stuttering is a disorder which may cause a child to repeat initial sounds or whole words, to prolong certain sounds, or have a complete block with no speech at all.

The people who see a child regularly can play an important role in deciding whether he or she does have a communication problem that may need special attention. It may be helpful to consider the following in that decision: Does the child talk like other children of his or her age? Is the child's ability to communicate or to understand what is said so limited that it keeps him or her from participating fully with other children?

Feelings about having a speech impairment

One of the children in *Feeling Free* (Reading, MA: Addison-Wesley Press, 1979) puts into words what many children with communication disorders may feel.

> When it's real hard for me to say things, I have to keep practicing them over and over in my head. I have to think before I talk. I really have to concentrate because for me the words don't come out naturally, like they do for hearing people. But talking is important to me. I want people to understand me, so I never give up.

> I guess the toughest thing is to start talking in front of people who have never heard me speak before, like when I go into a store for the first time. Sometimes I get a little nervous. I start rehearsing what I'm going to say before I walk in the door. When I finally do go in and start talking, people understand me after all. (1)

Another child said:

> The most wonderful thing about being able to pronounce my sounds now is that people aren't always saying 'What? What's that?' I bet I've heard that fifty thousand times. Often they'd shout at me as though I were deaf and that usually made me talk worse. Or they'd answer 'YES,' when that just didn't make sense. (2)

(1) Reprinted for *Feeling Free*, 1979, American Institutes for Research by permission of Addison-Wesley Publishing Company, Inc., Reading, MA 01867. All Rights Reserved.

(2) Payne; Kauffman; Patton; Brown; DeMott. *Exceptional Children in Focus*. Columbus, OH: Merrill Publishing Co., 1979.

Puppets that depict speech impairments

Several of the PACER puppets have speech disorders. Jay, because of his hearing impairment, has never heard speech. Thus, articulation is poor and the voice has a monotone quality. Another puppet Sally, with impaired muscular coordination because of her cerebral palsy, struggles to speak and has exaggerated head and mouth motions, but she can be understood quite well.

This material was reviewed and updated by Eleanor Swanson, a speech pathologist, PACER board member and a life member of Minnesota Speech-Language-Hearing Association.

Resources

Books for children

(P = Primary, M = Middle, U = Upper grade level recommendations)

Christopher, Matthew. *Glue Fingers*. Boston, MA: Little, Brown and Co., 1975. Bill Joe is reluctant to play football because he stutters. (M, U)

Corcoran, Barbara. *A Dance to Still Music*. New York, NY: Atheneum, 1974. A 14-year-old girl, newly deaf, doesn't want to speak because she can't control her own voice. (M, U)

Green, Phyllis. *Walkie-Talkie*. Addison-Wesley, 1978. This is a powerfully told story of the strange relationship of two friendless boys: Richie, a 14-year-old, two years behind in school, hyperactive and frequently inclined to exhibit behavioral problems; and Norman, a 13-year-old boy with severe cerebral palsy. He uses a wheelchair and has difficulty with speech. (M, U)

Kelley, Sally. *Trouble With Explosives*. New York, NY: Bradbury Press, 1969. Story about a child who stutters. (M, U)

Lee, Mildred. *The Skating Rink*. New York, NY: The Seabury Press, 1969. Fifteen-year-old Tuck Farady overcomes his self-consciousness about his stuttering on the skating rink. (M, U)

Levine, Edna. *Lisa and Her Soundless World*. New York, NY: Human Services Press, 1974. The efforts of a girl who is deaf to talk. (P, M, U)

Stanek, Muriel. *Growl When You Say "R"*. Whitman, 1979. With the help of his speech teacher, Robbie overcomes his problem. (P)

White, E. B. *The Trumpet of the Swan*. New York, NY: Harper and Row, 1970. A fantasy of a trumpeter swan who is born without a voice but learns to play a trumpet.

Books for adults

Ainsworth, Stanley. *Stuttering: What It Is and What to Do About It.* Lincoln, NE: Cliff Notes, 1975.

Allen, K.E.; Holm V.A.; Schiefelbusch, R.L., eds. *Early Intervention — The Team Approach.* Baltimore, MD: University Park Press, 1978.

Anderson, Virgil; Newby, Hayes. *Improving the Child's Speech.* Oxford University Press, 1973. Practical suggestions.

Barach, Carol. *Help Me Say It: A Parent's Guide to Speech Problems.* New York, NY: New American Library, 1983. Normal speech and language development is outlined, followed by chapters on various types of communication disorders and how they can be identified and remedied by parents and professionals.

Cooper, Eugene. *Understanding Stuttering: Information for Parents.* National Easter Seal Society, 1976. Informative booklet on ways parents may work with speech pathologists in treating their stuttering child. Aims at alleviating guilt some parents may feel.

Cooper, J.O.; Edge, D. *Parenting Strategies and Educational Methods.* Columbus, OH: Charles E. Merrill, 1978.

deVilliers, Peter; deVilliers, Jill G. *Early Language.* Cambridge, MA: Harvard University Press, 1979. The book covers obstacles to language development such as deafness, aphasia and autism.

Fallen, N.H. with McGovern, J.E. *Young Children with Special Needs.* Columbus, OH: Charles E. Merrill, 1978.

Hayden, Alice; McGinnes, G. "Basis for Early Intervention". Sontag, El; Smith, J. Certo, eds. *Educational Programming for the Severely and Profoundly Handicapped.* Reston, VA: Council for Exceptional Children, 1977.

Massengill, Jr., Raymond; Phillips, Phyllis, P. *Cleft Palate and Associated Speech Characteristics.* Cliff Notes, 1975. Overview for parents of children with cleft palate, its correction, and treatment of special problems.

Partners in Language: A Guide for Parents. American Speech-Language-Hearing Association, 10801 Rockville Pike, Rockville, MD 20852, 1973.

Schreiber, Flora R. *Your Child's Speech.* Ballantine, 1973. It includes sources for help. Practical ideas on how speech and language development can be encouraged.

Schwartz, Sue; Miller, Joan E. Heller. *The Language of Toys: Teaching Communication Skills to Special-Needs Children.* Rockville, MD: Woodbine House, 1988. Contents include background information on language development and delays and detailed suggestions for how to use toys, along with sample language dialogues arranged sequentially by language developmental age from birth to 60 months.

Van Riper, C. *Speech Correction: Principles and Methods.* (6th ed.) Englewood Cliffs, NJ: Prentice-Hall, 1978.

Wicka, Donna K.; Falk, M. *Advice to Parents of a Cleft Palate Child.* Springfield, IL: Charles Thomas Publishers, 1970. The work of professionals is summarized.

Wiig, E.H.; Semel, E.M. *Language Assessment and Intervention with the Language Disabled.* (2nd ed.) Charles E. Merrill, 1984.

Films

Films with an * are available from University Film and Video, Suite 108, 1313-5th Street SE, Minneapolis, MN 55414, (612) 627-4270.

Everyone Needs Some Help. (Like You, Like Me Series) (6 min., color, sound, 16 mm, 1977, 3E1167) Manuel, who stutters, and his friends plan a swap meet to trade items they've made. He wants to sing a song at the meet, because he never stutters when he sings. Others think of disabilities they cope with.

The Breakthrough. * (40 min., color, sound, 16 mm, 1981, 9D0607) For senior high students, this film shows people with cerebral palsy that cannot speak. Using a pictographic symbol language to communicate. Bliss symbolics.

Organizations

National organizations:

American Speech-Language-Hearing Association
10801 Rockville Pike
Rockville, MD 20852
(301) 897-5700

National Center for Stuttering
200 E. 33rd Street
New York, NY 10016
Toll-free phone: 1-800-221-2483

Speech Foundation of America
152 Lombardy Road
Memphis, TN 38111

State organizations and agencies are listed in Additional Resources Section at end the of the manual.

Physical Disabilities

P.L. 94-142 defines orthopedically handicapped as "a severe orthopedic impairment which adversely affects a child's educational performance." The term includes impairments caused by congenital anomaly (birth defect: e.g., clubfoot, absence of some limb, spina bifida); impairments caused by disease (e.g., polio, multiple sclerosis, etc.); and impairments from other causes (e.g., cerebral palsy, amputations, spinal cord injury.)

Many children who are orthopedically impaired have average or above average intelligence and can function in a mainstream classroom situation. Most of them may need to be provided with adaptive aids for learning or the help of a teacher's aide.

In 1989-90, the total number of children in Minnesota receiving special education because of physical impairments was 1,331.

Listed below are the physical disabilities most commonly affecting children.

Cerebral Palsy

What is cerebral palsy?

Cerebral palsy is a permanent disability caused by damage to the brain. **Cerebral** refers to the brain and **palsy** refers to lack of control over the muscles. The term cerebral palsy includes a large number of neuromuscular disorders of differing severity levels and varying symptoms.

For the disorder to be classified as cerebral palsy, not only must there be a problem with muscle movement or posture, but also the problem must occur early in development at the time of the brain's most rapid growth. In some cases, the muscular disorder may be accompanied by mental or emotional impairment, convulsive seizures (called epilepsy), or losses in hearing, vision, or the other senses. Some of these associated conditions can be treated successfully and some kinds of cerebral palsy can improve with intervention. However, the nerve cells involved are limited in their powers of repair and regeneration.

Injury to the brain that results in cerebral palsy usually occurs before, during, or shortly following birth. The chief cause is an insufficient amount of oxygen reaching the brain in the fetus or newborn child. Other factors may include maternal viral illness, blood incompatibility, or viruses or bacteria which attack the infant's central nervous system. The disorder occurs in about four out of every 1,000 persons. At the present time, there are an estimated 750,000 Americans with cerebral palsy, and approximately 9,000 new cases occur every year.

The condition cannot be inherited. There are three main types of cerebral palsy. The most common type is called **spastic** cerebral palsy. The muscles are tense in contracting. When reflexes are tested, responses may be very brisk, resulting in repeated contractions. If a child with spasticity is supported under the arms, the legs often lay straight down, unable to flex at the knees. The lower legs turn in and cross at the ankle. The movements of the legs are stiff and resemble the cross blade of a pair of scissors, hence the term "scissors gait." This condition can sometimes be corrected by surgery.

The second type, **athetoid**, is characterized by involuntary movements of affected parts of the body. This incessant, slow activity is called **athetosis**. The hands may turn in and twist and there may be facial grimaces, poor tongue control and drooling. Another form of involuntary movements occurring with athetosis involves abrupt flailing or jerky motions of the body.

The third type of cerebral palsy is called **ataxia**. The principal movement disturbance is lack of balance and coordination. Persons with ataxia may sway when standing, have trouble maintaining balance, and often walk with feet spread wide apart to avoid falling.

Depending on the degree of motor impairment, most persons with cerebral palsy can be very self-sufficient with appropriate adaptive aids and appliances.

Feelings about having cerebral palsy

The feelings of having cerebral palsy as written by LeAnne Dahl, who has cerebral palsy, are reflected in the following narratives:

> All children and grownups experience many kinds of feelings during their lifetimes. All of us should learn that having feelings and being able to talk about them to our parents, teachers or friends is good. Whether one feels good, bad, angry, or sad, he or she should not be afraid to tell others. By saying how we feel, we show that we have the courage or are strong enough to talk about our disabilities, and to be honest.

For example, in the following story, a brother helps his sister make a new friend:

Sarah

One day Jenny was jumping rope in front of her house. Suddenly, she saw a boy about 12-years-old pushing a girl in a wheelchair. They stopped when they got to Jenny.

"Hi," said Jenny. "Where are you going?"

"Hi," said the boy. "I'm taking my sister Sarah out for a walk. My name is Tom. What's yours?"

"Jenny." The girl was quiet for a while as she stared at the girl in the wheelchair. Then she asked, "What's wrong with you, Sarah? Were you in a car accident?"

"No, I was born with cerebral palsy," answered Sarah.

"But, you have legs. Why don't you walk?" said Jenny as she pointed to Sarah's legs.

"Well, the muscles don't work right because my brain was injured and it doesn't send messages correctly to my legs. That is, they look okay but they don't work right. The doctors says that with therapy maybe some day I'll walk in some way, but maybe not."

"Oh, that's too bad," Jenny said. "Doesn't that make you sad or mad?"

"Well yeah, sometimes I get mad that I can't get up and run across the park . . . then I feel sad, too. But most of the time I'm a happy person. There are lots of things I can do and that's what I work on the hardest."

Jenny replied, "I wish you could run and jump rope like me. Do people ever make fun of you because you use a wheelchair?"

"Sometimes younger kids do, but I just explain why I use this chair and most of the time they understand."

"I guess I will try to remember to never laugh at you or anyone that does things different than me," said Jenny.

"That's great!", said Tom. "Say, why don't we have a picnic tomorrow at our house?"

"Oh, I'd like that! Could we, Tom, could we?" asked Sarah. "Would you come, Jenny?"

"Yes, oh yes!" Jenny smiled with joy as she reached out for her new friend's hand.

Puppet used to portray cerebral palsy

Sally, the puppet used for COUNT ME IN presentations to depict cerebral palsy, is affected in such a way that she cannot walk, so she uses a wheelchair. Sally's speech is also difficult to understand, so children may have to listen very carefully.

The puppet's hands do not work very well. It is easier for her to write with a large pencil or crayon, to brush her teeth with an electric toothbrush, and

play card games with a special holder for the cards. Sometimes, the puppet does her homework on the cassette tape so the teacher can listen to it. A computer with a key guard that allows her to select one key at a time while resting her hand atop the computer without touching too many keys at once has been an excellent assistance in doing homework and producing legible work. The puppet talks about learning to swim and to even play soccer, using the wheelchair to kick the ball.

This information about cerebral palsy was reviewed and updated by Joan E. Brintnall, executive director of United Cerebral Palsy and Maria Anderson, coordinator of the Early Childhood Family Training Project at PACER Center, who is the parent of a daughter who has cerebral palsy.

Resources

Books for children

(P = Primary, M = Middle, U = Upper grade level recommendations)

Aiello, Barbara; Shulman, Jeffrey. *It's Your Turn at Bat.* Frederich, MD: Twenty-first Century Books, 1988. A fifth grade boy with cerebral palsy discovers money that he was responsible for is missing. Includes a question and answer section about what it's like to have cerebral palsy. (M, U)

Chinn, Richard H. *Each Step of the Way.* Johnston, PA: Matex Association, Inc. 1975. This autobiography emphasizes the teen years and early adult years with a person who has athetoid cerebral palsy.

Emmert, Michelle. *I'm the Big Sister Now.* Niles, IL: A. Whitman, 1989.

Fassler, Joan. *Howie Helps Himself.* Chicago, IL: Albert Whitman and Co., 1975. A child with cerebral palsy. An account of how the child feels.

Green, Phyllis. *Walkie-Talkie.* Addison-Wesley, 1978. Powerfully told story of two friendless boys: Richie, age 14, hyperactive and frequently inclined to malicious actions, and Norman, age 13, in a wheelchair due to severe cerebral palsy, and he has garbled speech.

Perske, Robert. *Don't Stop the Music.* Abingdon Press, 1986. Action-packed novel about two teens with cerebral palsy.

Pursell, Margaret Sanford. *A Look at Physical Handicap.* Lerner, 1976. A description of the many ways one can be physically disabled that first graders can understand and that sixth graders will find interesting.

Robinet, Harriette. *Jay and the Marigold.* Chicago, IL: Children's Press, 1976. A young boy born with cerebral palsy watches a flower grow and learns he, too, can grow and blossom. (P, M)

Roy, R. *Move Over, Wheelchairs Coming Through!* New York, NY: Clarion Books, 1985. 83 pages. Written for school-age children. Text and photographs tell the stories of seven youth with disabilities between the ages of 9 and 19 who use wheelchairs in their active lives.

Whinston, Joan Lenett. *I'm Joshua and Yes I Can.* Voorhees, NJ: Joshua Books, 1989. A first grade boy's fears and insecurities about his first day at school and his cerebral palsy.

Books for adults

Crossley, Rosemary; McDonald, Anne. *Annie's Coming Out.* This famous book is the story of a young Australian woman who was institutionalized and the therapist who recognized her communications and assisted her education and her ultimate release from the institution.

Finnie, N. *Handling the Young Cerebral Palsied Child at Home.* London, England: Dutton, 1975. Comprehensive information about specific care.

Geralis, E., ed. *Children with Cerebral Palsy: A Parent's Guide.* Rockville, MD: Woodbine House, Fall, 1990. This 350 page book is a comprehensive reference for families of

children with cerebral palsy. It contains information about the child's needs in health care, home care, education, legal rights, and long-term care.

Jewell, G. *Geri*. William Morrow and Company, New York, NY: 250 pages. A warm, funny and moving account of a courageous young woman's rise to stardom and her triumph over cerebral palsy.

Joel, Gil S. *So Your Child Has Cerebral Palsy*. University of New Mexico Press, 1975.

National Easter Seal Society. *Cerebral Palsy: Dr. Meyer Persteen Answers Questions Parents Ask*. Illinois.

Perske, Robert. *Circles of Friends*. Nashville, TN: Abingdon Press, 1988. People with disabilities and their friends enrich the lives of one another.

Robinault, Isabel P., ed. *Functional Aids for the Multiply Handicapped*. Lippincott, 1973. Prepared under the auspices of the United Cerebral Palsy Association, this helpful resource book incorporates information on and pictures of hundreds of functional aids and pieces of equipment. The developmental range from infancy to maturity is covered.

United Cerebral Palsy of Minnesota. *Health Care Coverage and Your Disabled Child: A Guide for Parents*. This 31-page booklet answers many questions parents might have about health care coverage for their children. It describes types of insurances, HMOs, and alternative ways to finance health care.

U.S. Dept of Health and Human Services. *Cerebral Palsy: Hope Through Research*. 1980. This 25-page booklet describes current theories about the causes of cerebral palsy and research for prevention and treatment.

Films

Cerebral Palsy, Hands On. (30 min. video, 1/2" VHS, 1989) Detailed examination of what cerebral palsy is. University of Washington, Instructional Media Services.

Like A Person. (16 min. color video, 1/2" VHS, 3/4" U-Matic, 16mm, 1988) Examines cerebral palsy, the people who have it, and what the United Cerebral Palsy Association does to aid and educate people.

MelonWheels. (19 min., color, sound, 16 mm, SE1446, 1982) Mel's severe cerebral palsy kept him away from the world until he was 49. He is now involved with community and friends.

Spina Bifida

What is spina bifida?

Spina Bifida (spy-nuh bi'-fi-duh) is a congenital defect which is present at birth. Literally, it means "open spine" or "Spine split in two." One or more of the spinal vertebrae fail to close completely, leaving an opening in the spine. While the cause is not known, it appears to be a combination of environmental and genetic factors.

The most common and serious form of spina bifida causing lasting effects for the child is **myelomeningocele**. The spinal cord protrudes through the opening in the spine often forming a sac (the opening is surgically closed shortly after birth). Since this opening usually occurs at the lower end of the spinal cord, control of the legs, feet, bladder and bowels can be affected in varying degrees. These can range from mild weakness to complete paralysis; 80% of the children develop hydrocephalus, "water on the brain," which requires a shunt surgery usually the first week after birth.

The resulting disability varies with each individual. Some children with spina bifida have little or no disability. Yet, others have varying degrees of paralysis of the legs and incontinence (lack of bladder and bowel control), which can sometimes be helped through surgical procedures or artificial devices. Cognitive and learning difficulties can occur from the hydrocephalus.

Parents and teachers need to check for the presence of skin or pressure sores, since the child has no sensations in the buttocks and lower extremities and will spend long hours in braces or wheelchair. Also important in the child's life is a good understanding of psycho-social concerns presented by the disability.

Education requires adaptations for physical needs, but as much as the child has good use of the upper part of body, other modifications are minimal. Educators should be aware of the possibility of learning problems secondary to the hydrocephalus. The child often has a good vocabulary and verbalization but has difficulty with comprehension skills.

Feelings about a child with spina bifida

"For six years, since my daughter's birth, I have been experimenting with various methods of explaining Jill's differences to nieces and nephews, neighbor children, and most recently, classmates. Perhaps some of my experiences can be helpful.

"Whenever possible I think the child with spina bifida should answer questions and give explanations about herself with assistance from adults when needed. Very often questions about Jill are asked of me even when she is present. By directing the question back to Jill, the focus becomes Jill, as a person, rather than an object to be talked about. Answering questions about herself is not difficult for Jill now, although she is extremely brief and to the point: 'I use a wheelchair because I can't walk. My legs don't work. It was that way when I was born.'

"Before Jill was able to explain and now when further explanation is necessary, I've found that short, non-medical explanations are best. Of course, terminology should be varied depending on the student's age.

"For young elementary aged children, my explanation has been: 'Jill was born with a hole in her back. The doctors fixed it, but her legs still don't work. So, she uses a wheelchair to get around.'

"For older elementary children who especially seem to want (or need) more details, I elaborate: 'Jill was born with a hole in her spine. The doctors repaired it, but nerves that should have gone to the muscles in her legs didn't make it past the hole. Without nerves, the muscles don't work, so Jill's legs can't hold her up for standing or for walking. She is paralyzed from her waist down and uses her wheelchair to get around.'

"It has been my experience that these brief explanations are very satisfactory for most children. Lengthy, medical conversations are sometimes frightening, often boring, and almost always more than anyone wants to know.

"One thing children of all ages seem to be interested in is Jill's wheelchair. When starting kindergarten last year, Jill's teacher had her 'show and tell' about her chair: the wheels, the brakes. She stressed that it isn't a toy, and that Jill works it very well herself and should be asked if she'd like a push. Some children seem to benefit from actually using Jill's chair, and since she isn't bothered by this, we allow it when it seems appropriate.

"An attitude that I believe causes some difficulty for children is differentness — that because a child with spina bifida is physically different, then everything about them is different. As the mother of a six-year-old who is physically different, I would like to see equal emphasis placed on the sameness of all children. Maybe my daughter said it best when I asked her recently what would be some important things I should say when describing her:

I have curly hair that's too short for barrettes.
My favorite color is green.
I'm six years old.
I have a baby sister.
I go to school every day.
I hate worksheets when they're hard.
I take swimming lessons at the "Y."
My favorite thing to do is play with friends.
I love chocolate pudding.

Puppet used to portray spina bifida

Sally is the puppet that is used for both the cerebral palsy and spina bifida scripts. However, she never portrays both disabilities in the same show. In the spina bifida script, her legs are paralyzed, and she does not have bladder or bowel control. She wears special underwear and controls her bowel movements with diet. Sometimes, kids tease her. She shares her feelings about that in the script.

She is strong in her arms and does not have speech problems like Sally, who has cerebral palsy. She is asked a lot of questions about her wheelchair, how she dresses, etc. See the section on Sally with cerebral palsy, but remember the differences between the disabilities when answering the students' questions.

The information about spina bifida was written by Christy Bateman, a member of PACER's Board of Directors and Dr. Ronald Bateman, a former PACER Board member. Both are parents of Jill.

Resources

Books for children

(P = Primary, M = Middle, U = Upper grade level recommendations)

Bennet, Carol J. *Giant Steps for Steven.* 1111 Belrose Road, Mayfield Heights, OH, 44124. Afterschool Exchange, Inc. Preschool child with spina bifida. Simple test, large photos of Steven using braces, wheelchair, etc. (P)

Hawker, Frances; Withall, Lee. *With a Little Help From My Friends.* Jacaranda Press, 1979. Black and white photographs illustrate the story of Peter, who has spina bifida. Peter goes to school where he helps the children understand his disability. (P)

Pence, Barbara; Nelson, Gloria. *You Are Special - You're the One.* Coloring/story book of Holly, a little girl with spina bifida. (P)

Rabe, Berniece. *The Balancing Girl.* ACCH Books for Children and Teenagers. Margaret, who uses a wheelchair, thinks up a nifty idea for her school fair. Grades K-3 (P, M)

Rabe, Berniece. *Margaret's Moves.* ACCH Books for Children and Teenagers, 1987. Here's *The Balancing Girl* a few years later. Born with spina bifida, 10-year-old Margaret longs to be able to keep up with other children, especially her brother . . . and her desire for a lightweight sports chair.

White, Paul. *Janet at School.* New York, NY: Thomas Y. Crowell Co., 1977. A five-year-old with spina bifida goes through the school day with her classmates without disabilities.

Books for adults

Bloom, Beth-Ann; Seljeskog, Edward. *A Parents' Guide to Spina Bifida.* Minneapolis, MN: University of Minnesota Press, 1988, (612) 624-2516.

Cerone, Sharon Bidwell; Meyers, Gary J.; Olson, Ardis L. *A Guide for Children with Spina Bifida.* Springfield, IL: Charles Thomas, 1981.

Chapman, Warren; Hill, Margaret; Shurtleff, David B. *Management of the Neurogenic Bowel and Bladder.* Oak Brook, IL: Eterna Press. Technical but excellent discussion of implications, treatment, and management of children and adults with neurogenic bowels and/or bladders, specifically in cases of spina bifida, spinal cord tumors, or trauma.

McLone, David. *Introduction to Spina Bifida.*

Peiper, Elizabeth. *Sticks and Stones.* Syracuse, NY: Human Policy Press, 1977. A mother's account of giving birth to and raising a son with spina bifida.

Peiper, Elizabeth. *The Early Years and the Child With Spina Bifida.* The focus is on the early stages of development for children with spina bifida.

Peiper, Elizabeth. *The Teacher and the Child With Spina Bifida.*

Swinyard, Chester. *The Child With Spina Bifida.* New York, NY: Association for the Aid of Crippled Children, 1971. Available from: Spina Bifida Association of America, Suite 540, 1700 Rockville Pike, Rockville, MD 20852. (301) 770-7222; HOTLINE: 1-(800) 621-3141.

Williamson, G. Gordon. *Children With Spina Bifida, Early Intervention and Preschool Programming.* Baltimore, MD: Paul H. Brookes Publishing Co., 1987.

Spinal Cord Injury

Spinal cord injury can occur through an accident (such as diving, parachuting errors, broken back, or severe whiplash) or illness, and can result in varying degrees of paralysis and loss sensation.

Total paralysis which affects all four limbs as well as some body functions is referred to as **quadriplegia.** Partial or total paralysis for either the upper limbs or the lower limbs is referred to as **paraplegia.**

It is not unusual for individuals with paralysis to lack skin sensations and feelings of pain. This may present problems. For example, the child with paralysis in the lower extremities would not feel scalding bath water and could be unintentionally burned. Shoes and socks must be fitted and checked carefully to prevent skin damage to the feet. Also, bowel and bladder paralysis often occur in cases of quadriplegia and paraplegia.

Spinal cord injuries usually do not affect the ability of the child to learn. Intelligence varies from individual to individual, just as in the general population. However, adjustments can and should be made in the classroom - so that it is easier for a student with a physical disability to manage to do the work and participate in activities with his or her peers.

Resources

Books for children

(P = Primary, M = Middle, U = Upper grade level recommendations)

Savitz, Harriett May. *On the Move.* New York, NY: The John Day Co., 1973. A story about young persons who are paraplegics for whom wheelchair basketball is a means of fun and growing up. (M, U)

Savitz, Harriett May. *Janet at School.* New York, NY: John Day, 1970. Two young people who are paraplegics get caught up in training to enter the Paraolympics in Israel. (M, U)

Books for adults

Chapman, Warren; Hill, Margaret; Shurtlerff, David B. *Management of the Neurogenic Bowel and Bladder.* Oak Brook, IL: Eterna Press. Technical but excellent discussion of implications, treatment, and management of child and adults with neurogenic bowels and/or bladders, specifically in cases of spina bifida, spinal cord tumors or trauma.

Fergusson, Martha. *Sexual Adjustment: A Guide for the Spinal Cord Injured.* IL: Accent on Living, Inc., 1974.

Muscular Dystrophy (Duchene Type)

What is muscular dystrophy?

Muscular dystrophy is the name given to a complete set of diseases characterized by the progressive degeneration and weakening of voluntary muscles. There are many types of muscular dystrophy and persons of any age can be affected. However, the most common form of muscular dystrophy, is called **Duchene muscular dystrophy**. It affects only male children, and one in every 3,500 male babies in the United States. There are approximately 10,000 children in the United States with Duchene muscular dystrophy.

Causes

Duchene muscular dystrophy is an inherited disease transmitted to the child through a defective gene. It follows the recessive X-linked inheritance pattern. The disease is passed from the mother, who is a carrier but does not have the disease, to her sons. Each male child born to a carrier mother has a 50% chance of having the disease. Each female child born to a carrier mother has a 50% chance of being a carrier herself. Occasionally, a child will develop Duchene type muscular dystrophy when there is no prior family history of the disease. These are called "sporadic" cases and are thought by some to be the result of gene mutation.

Symptoms

The onset of Duchene muscular dystrophy usually occurs between the ages of two and six. Parents may notice that their child is particularly awkward or clumsy. He may tip-toe when walking. As the disease progresses, the child has difficulty getting up from a lying or sitting position. He begins to walk with his shoulders back and his abdomen protruding. He uses a waddling gait. Frequently the child's calf muscles appear to be enlarged. This is due to the replacement of healthy muscle with fat and connective tissue.

Tests for muscular dystrophy

Several clinical tests are used to positively identify the disease:

Electromyogram: In this test, the electrical activity of the muscle is measured. The electrical activity of a diseased muscle is distinctly different from that of healthy muscle.

Serum Enzyme Tests: These tests measure the amount of muscle protein in the blood. When muscles are healthy, relatively little muscle protein is present in the blood. A high level of muscle protein indicates diseased muscle tissue. High levels of the protein creatine phosphokinase (CPK) are one of the most important indicators of Duchene muscular dystrophy. This test can also be used on females to determine the likelihood of them being a carrier. Genetic counseling is advised if the tests are positive.

Muscle Biopsy: A small piece of muscle tissue is surgically removed and examined under a microscope. Muscle tissue of a person with muscular dystrophy shows abnormal fiber development and the presence of fat and connective tissue. Duchene muscular dystrophy is progressive with no remissions. The muscle degeneration follows a distinctive pattern beginning in the feet, legs, and pelvis moving upward to chest and shoulder muscles. It eventually involves all muscle groups.

Treatment

Presently, there is no cure for muscular dystrophy, but new research is offering hope. There is no medication or treatment that can stop or slow the progressive degeneration of muscle tissue. The treatment for this disease involves careful monitoring, physical therapy, orthopedic devices, and occasionally, surgery in order to insure maximum mobility and independence. One of the surgeries is a back surgery where rods are inserted alongside the spine to hold the torso erect. This eliminates curvatures of the spine and helps to stabilize the child. Stamina is increased because the child does not have to expend so much energy in holding himself up. The organs of the body are not crowded. Physical therapy, usually daily stretching of muscles, is used to prevent muscles from contracting. Muscle contracture is due to the weakening of some muscles and the over-pull of others. Severe contractures cause joint deformity and make walking difficult. Occasionally, surgery is necessary to release contracted muscles and to give the child more mobility. Orthopedic aids such as plastic leg braces, canes, and walkers are usually prescribed as the muscles in the legs deteriorate. These aids help keep the child ambulatory as long as possible. Usually by pre-adolescence (ages 9-1/2 to 12-years-old), the child with Duchene muscular dystrophy uses a wheelchair. As the disease progresses and the pectoral muscles weaken, respiratory equipment and antibiotic therapy are used to facilitate breathing and prevent pulmonary infections. Few persons with Duchene muscular dystrophy live beyond their early 20's.

Education can be a most meaningful part of the child's life. During the early stages of muscular dystrophy, the child should be encouraged to continue in the regular classroom and school programs.

Adaptations for school and eventually home-bound instruction may need to be considered as the disability progresses. In recent years, most students are completely or partially mainstreamed and have been able to graduate with their class. Some students with muscular dystrophy go on to trade schools, work part-time, and seek out independent living opportunities with the aid of a personal care attendant. One parent aptly stated that young people with muscular dystrophy learn to balance hope for the future with reality.

New studies in muscular dystrophy have shown that immature muscle cells called myoblasts, which normally help repair muscle fibers, have been injected into the mice and fused with muscle fibers. Once inside a fiber, the myoblast nucleus, or core, provided a gene that allowed the fiber to begin producing dystrophin. Dystrophin is a protein that children with muscular dystrophy lack. Donald Wood, director of research for the Muscular Dystrophy Association said that "This is the most exciting approach for human therapy that, in my opinion, has ever come along."

Puppet used to portray muscular dystrophy

Danny is the puppet who has muscular dystrophy. He tires easily and uses a wheelchair. He will not get better and the muscular dystrophy will get worse. He feels badly when he gets left out. Mitch asks a lot of good questions and finds he has a lot of the same interests. They decide to trade action figures from their collections and play a game on Danny's computer. Danny can beat anyone at Nintendo. No questions are fielded by the puppet. The adult tries to explore ways of including Danny with his peers. "You know, sometimes a kid like Dan needs a special friend like Mitch. What do you think you could do to make someone like Dan feel more comfortable?"

This information was reviewed and updated by Peg Williams, a PACER board member, co-founder of the MD Parent Support Group and parent of a son who has Duchene muscular dystrophy, and Pat Adams, who is a facilitator for the MD Support Group (known as "group" by the young men). Pat has a 21-year-old son who has muscular dystrophy.

Resources

Books for adults

Weisman, MaryLou. *Intensive Care*. New York, NY: Random House, 1982. The story of a mother raising her 16-year-old son who has muscular dystrophy. (Video available starring Liza Minnelli)

Pamphlets

The following pamphlets are available through Muscular Dystrophy Association, 810 Seventh Ave., New York, NY 10019, (212) 586-0808.

Muscular Dystrophy Association, New York, NY. *Muscular Dystrophy*. A definition of muscular dystrophy and a description of the eight most common forms of the disease.

Muscular Dystrophy Association, New York, NY. *Muscular Dystrophy Association Medical Services*. A description of the services offered by the Muscular Dystrophy Association plus a listing of MDA clinics in all 50 states.

Muscular Dystrophy Association, New York, NY. *What Everyone Should Know About Muscular Dystrophy*. An illustrated booklet describing symptoms, causes, progression and treatment of muscular dystrophy.

Siegel, Irwin M. *Everybody's Different, Nobody's Perfect*. An illustrated booklet giving straight-forward easy to understand facts and feelings about children who have muscular dystrophy.

Siegel, Irwin M. *101 Questions and Answers About Muscular Dystrophy*. A booklet written for the lay person wanting information about the diagnosis, prognosis and treatment of muscular dystrophy.

Magazine

MDA Newsmagazine, a quarterly magazine containing the latest medical information for clients and parents. Available from MDA Association, 810 Seventh Avenue, New York, NY 10019.

Films

The following film is also available for loan through the Muscular Dystrophy Association, 810 Seventh Ave., New York, NY 10019:

MDA - Patient and Community Services. A nine-minute film on services provided by the Muscular Dystrophy Association.

Juvenile Rheumatoid Arthritis (JRA)

What is JRA?

Juvenile rheumatoid arthritis (JRA) is a chronic disease that affects as many as 250,000 children in the United States. JRA, as it is referred to, is an auto-immune disease affecting the body's connective tissue. For some yet unknown reason, the body produces abnormal antibodies which attack, not bacteria or foreign substances, but normal body tissue. It is characterized by swelling around the body organs.

Cause

The cause of JRA is unknown. It is unrelated to climate, diet, or lifestyle. It is not thought to be inherited. The onset is usually between the ages of two and four, although it can occur at any age. It is more common in girls than boys. Juvenile rheumatoid arthritis usually manifests itself in one of three forms:

Types of JRA

Systemic Juvenile Rheumatoid Arthritis - This affects both boys and girls equally. It is characterized by frequent, high, spiking fevers and a flat, pink rash, and enlarged lymph nodes. Many joints are affected and, sometimes, there is inflammation in the outer lining of the heart and lungs. The attacks may last for months but then disappear for months or years. Twenty percent of children with JRA have this form of the disease.

Polyarticular Juvenile Arthritis - This affects more girls than boys. It is characterized by the involvement of many joints, usually the fingers, hands, knees, hips, and ankles. Generally, joint involvement is symmetrical (same joint on both sides of the body). Forty to fifty percent of children with JRA have this type.

Pauciarticular Juvenile Rheumatoid Arthritis - This affects fewer joints, not symmetrically. Usually, the large joints are affected. Occasionally, there is inflammation of the iris of the eyes in children with Pauciarticular JRA, which can become serious if untreated. Thirty to forty percent of children with JRA have Pauciarticular arthritis.

Treatment

JRA is an unpredictable disease. At times, it seems to go away completely. This is called a **remission**. A remission can last for months or even years. At times it gets much worse. This is called a **flare**. Although there is no cure for JRA, 60-70% of the children with this disease do not suffer permanent joint damage. The disease often goes into permanent remission after 10 years.

Long lasting inflammation damages the surface of the joints. Joint inflammation can also affect the growth centers in the bones causing delays in the child's growth and development. The principal treatment of JRA is the controlling of inflammation and the protection of the joints which have become inflamed.

Aspirin is considered the safest drug for treating arthritis in children. Taken in sufficient amounts, aspirin reduces inflammation and decreases the pain of arthritis. Seventy-five percent of children with JRA require no other medication. In very severe cases,

doctors may prescribe antimalarial drugs, gold injections, or corticosteioids. Exercise is essential to the child with arthritis. A proper exercise program will help relieve stiffness, maintain flexibility and prevent joint deformity. Every child with JRA should have an exercise program individually designed by a physiatrist (doctor of physical medicine) or a physical therapist. Affected children should be encouraged to be physically active. Although contact sports must be avoided as well as any sport that involves jumping or running for long periods of time, there are many activities appropriate for the child with JRA. Roller skating, biking, swimming, and badminton all provide excellent, exercise opportunities and do no put undue stress on the joints. All children with JRA should be encouraged to participate in daily activities and to do as much as possible for themselves to build self-esteem and independence as well as to keep their joints and muscles flexible.

While exercise is important to maintain a range of motion and muscle strength, children with arthritis should avoid fatigue. Children with JRA frequently require more rest than other children. They may need to sleep later in the mornings and often need a nap or quiet rest time during the day.

Puppet used to portray juvenile rheumatoid arthritis (JRA)

Bridget is the puppet who has JRA. Sometimes, she has flare-ups and her joints get swollen and stiff. She gets irritable because of the pain and cannot participate actively in some sports during this time. She wears a splint on her hand to protect her wrist when it's sore and swollen. In the script, she answers a lot of Carmen's questions and asks Carmen to talk to Mitch about her arthritis. Mitch, who was mad at Bridget for not playing ball, finds a way to include her in the baseball team activities by being a scorekeeper and poster maker. Bridget answers questions at the end of this script. Many of which she discusses with Carmen in the text of the script, may be asked again by the students.

This material was reviewed and updated by Ceci Shapland, R.N., M.S.N. and regional technical assistance coordinator of CAPP (Collaboration Among Parents and Professionals) at PACER Center.

Resources

The following resources were provided by:

Arthritis Foundation National Office
Patient Services Department
Action for Childhood Arthritis Guide
Atlanta: Arthritis Foundation, Aug., 1985

Arthritis Foundation, Atlanta, GA, Patient Services Department, *Arthritis in Children, When Your Student has Arthritis*, 1989 and *We Can: A Guide for Parents of Children with Arthritis*, 1990. Available from Arthritis Foundation, 1314 Spring Street NW, Atlanta, GA 30309; (404) 872-7100.

Arthritis Foundation, Atlanta, GA. *Educational Rights for Children with Arthritis. A Manual for Parents*, edited by Linda L. Wetherbee; Amy J. Neil, 1989. Available from Arthritis Foundation, 1314 Spring Street NW, Atlanta, GA 30309; (404) 872-7100.

Arthritis Foundation, Tucson, AZ, Southwest Chapter. *Your Child with Arthritis - Why Eye Exams?* and *Message to Teachers*, 1983. Available from: Arthritis Foundation, P.O. Box 43084, Tucson, AZ 85733.

Arthritis Society, *About Juvenile Rheumatoid Arthritis*. Available from: The Arthritis Society, 920 Yonge Street, Suite 420, Toronto, Ontario, Canada M4W 3J7.

Brandt, K.D.; Schade, J. *Informational Guide for Parents of Patients with Juvenile Rheumatoid Arthritis (JRA)*. Indianapolis, IN: Indiana University School of Medicine, 1976, 13 pp. Adapted from: Brewer, E.J., *Parents' Manual: A Guide to Juvenile Rheumatoid Arthritis (JRA)* and *Chronic Arthritis*. Philadelphia, PA: Saunders, 1976. Available from: Kenneth Brandt, M.D., Indiana Univ. School of Medicine, Long Hospital, Rheumatology Div., 1100 W. Michigan St., Indianapolis, IN 46223; (317) 264-4225.

Brewer, E.J.; Giannini, E.H.; Person, D.A. *A Few Words to Parents about Juvenile Rheumatoid Arthritis (JRA) and Chronic Arthritis.* Houston, TX: Texas Children's Hospital, P.O. Box 20269, Houston, TX 77225.

Brewer, Jr., E.J.; Giannini, E.H.; Person, D.A. *Patient's and Parent's Physical Therapy Handbook.* Houston, TX: Texas Children's Hospital, 1982, 22 pp. Available from: Earl J. Brewer, Jr., M.D., Texas Children's Hospital, P.O. Box 20269, Houston, TX 77225.

Ferris, J.; Fujishge, C. *Do You Have a Child with Juvenile Rheumatoid Arthritis in Your Class?* and *Color Your Medication.* Available from: Arthritis Center of Hawaii, 347 North Kuakini St., Honolulu, HI 96817.

Giesecke, L.L.; Athreya, B.H.; Doughty, R.A. *Home Care Guide on Juvenile Rheumatoid Arthritis (for Parents)* and *Thanks to You a Child with JRA Will Succeed in School.* Available from: Dr. B.H. Athreya, Children's Hospital, 34th and Civic Center Blvd., Philadelphia, PA 19104.

Hicks, Raquel V. *Butterflies and Sunshine.* Designed for the adolescent or young adult with lupus. Attempts an explanation of the immune system; answers common questions asked by teens with lupus. Explains about compliance with treatment, self-care, diet, exercise, and unproven remedies. Available from: Pediatric Arthritis Center of Hawaii, Kapiolani Women's and Children's Medical Center, 1319 Punahou Street, Suite 734, Honolulu, HI 96826;

Written with Fujishige, Carole. *Kela's Body Builders.* Designed for parents of children with lupus or other collagen diseases. Pamphlet is a book of lists of foods and their values: High calcium, high potassium, high vitamin C, and high sodium.

Hollister, J. Roger. *Juvenile Rheumatoid Arthritis.* Available from: National Jewish Center for Immunology and Respiratory Medicine, 3800 East Colfax, Denver, CO 80206; (303) 388-4461; booklet, 36 pp.

Jones, P.A. *Game Plans for Children.* National Arthritis News, 3 (3):5,10, Summer, 1982. Available from: Arthritis Foundation National Office.

Kovalesky, Andrea. *School Checklist for Students with Juvenile Rheumatoid Arthritis.* Available from: Children's Hospital of Los Angeles, Rheumatology Department, (Attention: Andrea Kovalesky), 4650 Sunset Boulevard, Los Angeles, CA 90027; free.

Lowrance, M.A. *Jody's Advice, for Parents of Children with Juvenile Rheumatoid Arthritis* and *Jody Says, Do Your Exercises Every Day.* Available from: Arthritis Center of Hawaii, 347 North Kuakini St., Honolulu, HI 96817.

Madsen, Jane. *Please Don't Tease Me.* A girl with a physical disability called leukocytoclastic angitis, a disease which has resulted in deforming arthritis, asks for understanding. Available from: Judson Press, Valley Forge, PA 19481.

Parker, Elizabeth Hanson. *A Parent's Guide Towards Better Understanding of JRA: A Guidebook for Parents of Recently Diagnosed Juvenile Rheumatoid Arthritis Patients.* Available from: Children's Hospital of Los Angeles, Rheumatology Department, (Attention: Andrea Kovalesky), 4650 Sunset Boulevard, Los Angeles, CA 90027.

Reichenbecher, L., et al. *Arthritis Coloring Book: A Guide for Children and Their Families.* Houston, TX: Texas Children's Hospital, 1981, 17 pp. Available from: Rheumatology Dept., Texas Children's Hospital, P.O. Box 20269, Houston, TX 77225.

Shore, A.; Boone, J.E. *You, Your Child and Arthritis.* Toronto, Ontario: Arthritis Society, 38 pp. Available from: The Arthritis Society, 920 Yonge St., Suite 420, Toronto, Ontario, Canada M4W 3J7; (416) 967-1414.

Shulman, Marjorie. *Rheumatic Disease: A Primer for School Personnel and Parents.* Available from: Marjorie Shulman, Lookout Road, Norwalk, CT 06850.

Singsen, Berne; Breyfogle, Russell; Holsten, Donna; MacLaughlin, Cheryl; Polasik, Beverly; Rawlings, Scott; Schaberg, Sue. *You Have Arthritis Coloring Book: For Young People with Arthritis.* Available from: University of Missouri - Arthritis Center. Education Materials Request, c/o Donna J. Holsten, N403 Medicine, University Health Sciences Center, Columbia, MO 65212.

Williams, G.F. *Children with Chronic Arthritis: A Primer for Patients and Parents.* 1981, 364 pp. Available from: PSG Publishing Co., Inc., Littleton, MA 01460.

Ziebell, B. *As Normal as Possible: A Parent's Guide to Healthy Emotional Development for Children with Arthritis.* 1976, 60 pp. Available from: Arthritis Foundation, Southern Arizona Chapter, 3813 E. 2nd St., Tucson, AZ 85716.

The following is a list of videotapes. All tapes are VHS (1/2 inch) format, and they are available on a two-week free loan from:

AJAO
Arthritis Foundation
1314 Spring St., NW
Atlanta, GA 30309
(404) 872-7100

Special Needs of Chronically Ill Children in the School Setting Part 1. Wendy Cullar, Ed.D. In this tape, Dr. Wendy Cullar describes the federal laws which mandate the provision of special education services for children with arthritis and children with other chronic illnesses. The relationship of federal, state, and local laws is explained. In addition, Dr. Cullar makes suggestions to parents wishing to influence the provision of services at their children's schools. 27 minutes. Discussion Leader's Guide included.

Special Needs of Chronically Ill Children in the School Setting Part 2. David Wayne Smith, Ed.D. Dr. Smith describes federally-mandated school services available to children with arthritis. He describes a network of parent training centers which provide workshops to enable parents to be effective advocates. He also gives practical suggestions for parents to use in developing an Individualized Educational Program (IEP). In the ensuing discussion, parents and health professional describe their experiences working with schools. 24 minutes. Discussion Leader's Guide included.

Overview of Services to Health-Impaired Children — Past, Present, and Future. Harold O'Flaherty. In this tape, O'Flaherty describes services provided to children with health impairments through the programs of the federal government's Division of Maternal and Child Health. He explains the historical basis for these programs, describes the major initiatives which are underway, and describes the regional pediatric rheumatology center program. He also discusses the role that AJAO can take to ensure that high quality services are accessible to children with arthritis. 24 minutes. Discussion Leader's Guide included.

Overcoming Disabilities — Our Promise and Potential. Harold O'Flaherty. Using his own life and blindness as an example, O'Flaherty gives a motivating speech on overcoming disabilities. He describes his feelings and experiences while growing up, and outlines his four-point plan for enabling children with disabilities to reach their potential. 25 minutes. Discussion Leader's Guide included.

Orthopedic Problems and Joint Replacements in Children with JRA. Malcolm Granberry, M.D. Dr. Granberry, an orthopedic surgeon, discusses considerations regarding orthopedic surgery for children with arthritis. He describes four types of surgery, going over indications for the surgery, potential problems, and expected outcome. Dr. Granberry and members of the audience discuss the necessary commitment of the family and child for surgery to be successful. 33 minutes. Discussion Leader's Guide included.

Vocational Training, Education, and Career Opportunities. Gail Kershner Riggs, M.A. Gail Riggs

developed arthritis as a child, and she relates her experience and the philosophy of life which has led her to a successful career as an educator and health administrator. In addition, panel members discuss career education, vocational rehabilitation and job modification. 38 minutes. Discussion Leader's Guide included.

Maintaining Children within the School System. Balu Athreya, M.D.; and *Parent Advocacy Training*, Frank Donivan, Ph.D. In this tape, Dr. Balu Athreya outlines how his pediatric rheumatology center works with families and with school systems to maintain children who have arthritis. He emphasized the need to look for strengths in the child, to build on those strengths, and to plan for growth and not just focus on the illness. He outlines some barriers to remaining in school and discusses practical ways to overcome barriers.

Dr. Frank Donivan describes a workshop which is designed to equip parents with information about their legal rights and advocacy skills information which will enable them to deal effectively with their child's school system. 33 minutes. Discussion Leader's Guide included.

Eye Problems in Children with Rheumatic Diseases. Elbert Magoon, M.D.; James Cassidy, M.D. This tape focuses on eye problems which can occur in children who have rheumatic diseases. Dr. Magoon describes what happens when inflammation occurs in the eye, how it is detected, and how it is treated. Dr. Cassidy explores the risks of developing eye problems and the recommended frequency of eye examinations. The speakers emphasize the importance of eye care in the program in juvenile arthritis. 45 minutes. Discussion Leader's Guide included.

Multiple Sclerosis

Multiple sclerosis (MS) is a chronic disease of the central nervous system in which the simplest, everyday tasks can no longer be taken for granted. It attacks the white fatty tissue (myelin sheath) which is the coating around the message-carrying nerve fibers of the brain and spinal cord. Where myelin has been destroyed, it is replaced by plaques of hardened tissue (sclerosis). When this occurs in multiple places within the nervous system the result is multiple sclerosis - multiple because many scattered areas of the brain and spinal cord are affected; sclerosis because sclerosed or hardened patches of scar tissue form over the damaged myelin.

Nerve impulses are interrupted along the central nerves. This "short circuiting" of nerve messages leads to a variety of symptoms which may include tingling sensations, numbness, balance and coordination difficulties, weakness, vision, and/or speech problems. Symptoms can run the gamut from slight blurring of vision to complete paralysis.

Although approximately two thirds of those who have MS experience their first symptoms between the ages of 20 and 40 or even in their 50's, the disease may begin in childhood. It seems to occur at a higher incidence rate in cold climates. MS affects women 3:1 over men. An estimated quarter of a million Americans have MS, with nearly 200 new cases diagnosed every single week.

Multiple sclerosis is not contagious, it cannot be inherited, and it is rarely fatal.

There are no drugs that can cure MS, but there are medications that doctors can prescribe to offer relief of many symptoms.

Questions asked of persons with multiple sclerosis or MS

Is MS hereditary?

No. Recent research has helped scientists understand that persons may have a genetic susceptibility to MS. However, MS is a complicated disease and a person must also have something to trigger the disease process.

Isn't MS always progressive? And doesn't everyone with MS degenerate?

No. MS is not progressive for all individuals. The symptoms of MS vary greatly from person to person. For many people, symptoms of the disease flare up and then subside. When the disease is active, it is called an **exacerbation**. Symptom-free periods are called **remissions**. Some people have mild symptoms that do not change over time. Some people do experience an increase in symptoms over time. The complete spectrum can range from very mild, to intermittent, to a rapidly progressive form of the disease.

Can people with MS work and have families?

Yes! Many people with MS continue in their careers. Some people may need to adjust their jobs, but many people with MS work, play, and have families. Some adjustments to accommodate the symptoms of MS may need to be made.

The material on MS was reviewed and updated by Wendy Brower, manager of government relations for the Minnesota Multiple Sclerosis Society.

Resources

Books for children

English, Jennifer. *My Mommy's Special.* 1985. This mommy is in a wheelchair with MS. This book is mostly a photo picture book. The text is in big print that could work as a beginner's reading book. (P)

Books for adults

Siegelman, Sheila. *Sukey's Songbook of Multiple Sclerosis.* 1988. Not a children's book, but a wry and gritty collection of reflections and suggestion about "what to do with MS" from the experience of an educator who was disabled by MS in 1979.

National organizations:

National Multiple Sclerosis Society
205 East 42nd Street
New York, NY 10017-5706
(212) 986-3240

MS Toll-free Information Line
1-800-624-8236
Brochures, flyers and audio cassette tapes are available from the Multiple Sclerosis Society. Call the Minnesota North Star Chapter at 870-1500 or toll-free, 1-800-222-0008 (Voice and TDD).

Brittle Bone Disease

Osteogenesis imperfecta (OI), commonly known as brittle bone disease, is a very rare, inherited condition that begins in fetal life and often is evident at birth or during early childhood, but occasionally is not diagnosed until later. It occurs once in every 20,000 live births.

The three main signs of this disease are fragile bones that break very easily, blue sclera in the eyes, and conductive deafness caused by gradual formation of spongy bone tissue in the middle ear.

Children with osteogenesis imperfecta are usually smaller than average, have underdeveloped muscles, and must be careful in avoiding any activity that may result in broken bones. Laughing and coughing, even a loving hug, could lead to serious injury in a child with such a condition. Children with brittle bones may have to spend repeated periods in the hospital or have their limbs in casts.

Amputation

The most frequent causes of the loss of an arm, leg, hand or foot are from accidents, infections such as gangrene, or diseases such as cancer. However, children are sometimes born without limbs (a frequent birth defect in the 1960's among children whose mothers took the drug thalidomide during the early stages of pregnancy). In most situations, children and adults are fitted with a "prosthesis," artificial arm, hand, leg or foot.

With or without an artificial limb, most people with amputations do learn to dress, bath, cook, drive a car, and participate in most activities and occupations. In school, the child can learn to write, draw, and play games with his/her classmates. Some children are comfortable demonstrating their prosthetic devices and showing how they work.

Educational Programs for Children Who Have Physical Disabilities

Many children with physical disabilities are educated in regular classrooms with their peers who do not have disabilities. Those children whose orthopedic problems are extremely involved or who may have multiple disabilities are usually provided with a program in a special classroom or building that is specifically-equipped throughout for their varied needs. However, in either setting, children with motor impairments receive adaptive physical education as a part of their regular school program, as well as related services from various kinds of therapists:

an **occupational therapist** assists the student in the development of fine motor skills (such as cutting, pasting, writing) and eye-hand coordination and self-help skills (such as eating and dressing);
a **physical therapist** emphasizes the development of the large muscles, the gross motor skills such as walking, sitting, climbing, and includes the help needed with wheelchair, braces, crutches, etc.;

a **music therapist** or **recreation therapist** uses music or recreation activities to aid in the overall development of the child. Music and games can help muscles relax, speech and communication to flow more easily, and bodily motion to occur more spontaneously;

a **speech and language therapist, clinician**, or **pathologist** treats speech and language delays and disorders and works with each child to develop the best possible understandable communication skills.

According to Section 504 of the Rehabilitation Act of 1973, a school district must provide accessible programs for students who have physical disabilities.

When a child who has physical disabilities is in the classroom, the teacher should have an established procedure to follow in helping that child out of the building in a fire drill or other emergency. For example, if the child uses a wheelchair, two teachers or other adults should be prepared to carry the child out of the building, as elevators cannot be used. Children who have physical disabilities but are able to walk should be accompanied out of the building by an adult.

Independence for those with physical disabilities

The major problem confronting most persons with motor impairments is one of independence because of difficulties and restrictions in mobility. All children and adults want and should be allowed and encouraged to be as independent as possible. However, persons with orthopedic disabilities may be overprotected and often times assumed less capable because of their motor impairments.

Independence needs to be interpreted differently for each individual who is disabled, whether child or adult. A child with mild cerebral palsy may be able to do anything without special aids by just allowing extra time for each project. A child with paraplegia may need specific appliances for certain projects: a standing frame to get close to the family car to help scrub it clean, but a wheelchair for sitting again to hose off the suds. A motorized wheelchair may enable an older child who has quadriplegia to navigate independently around the house, yard, and neighborhood.

For adults, the most independent lifestyle many enjoy is living in their own home or apartment, where there may be adaptations. These adaptations allow full accessibility and ease, regardless of the degree of mobility difficulty. Kitchens and bathrooms with wide doors, homes with ramps, door levers instead of handles, and appliances adapted for lower working levels make independence possible.

Managing one's own lifestyle, coming and going as one is able, means total independence. Various types of public transportation for persons who have disabilities and adapted vehicles add to that freedom.

Sometimes it is necessary to have another person share the responsibility for daily needs. In many cases, individuals requiring personal care hire an attendant to assist in taking care of their needs. The attendant's duties can range from assisting the disabled person in and out of bed, to dressing, preparing meals, and shopping.

Semi-independent living options may include living in a group home where there are several people who have disabilities who need help with personal care and household duties. Or, it might include staying in one's family home where parents and siblings assist in the care. No matter which lifestyle is chosen, the real test of true independence is how the individual feels about himself/herself.

Three examples from persons at the Center for Independent Living in Berkeley, California, clarify the meaning of independence:

"Julie, who uses a wheelchair as a result of polio, majored in journalism in college and now works as a newspaper editor. She loves her work and is good at it. Julie admits that she faced many difficulties in reaching her career goal and is still overcoming obstacles. She has a very definite idea of what it means to be independent:

> I want to set my own goals and make the decisions that will affect my life. To me, that's what independence is all about.

"Dan, a quadriplegic who works as a clinical psychologist, has some opinions on these issues:

> I need the assistance of an attendant and I can't drive, yet I still feel that I am living an independent life. To me, independence doesn't mean being able to do everything, or not needing other people. I've been able to organize my life in a way that is very satisfying to me. I have a successful career, travel and enjoy cultural events in my city. I love being with people and have a lot of friends. Sure, I have some limitations, but who doesn't?

"Eric, a high school student who has speech and hearing disabilities, has a slightly different view of what it means to be independent:

> Independence means being fully me. I have a lot of feelings, abilities and dreams. Independence means freeing what's inside of me and letting it come out. I love to work on cars, and I'm really good at it. When I graduate I want to work as a car mechanic. I also enjoy writing poetry for fun. Because of my speech, I can express myself a lot better in writing. Who knows, some day, I might even write a book! I feel I have a lot to contribute to the world I live in."*

*Reprinted with permission from: *Taking Charge of Your Life: A Guide to Independence for Teens With Physical Disabilities.* Washington, DC: Closer Look, 1981, page 20.

Aids and appliances

For mobility -

Canes, crutches, braces, and wheelchairs are frequently used.

Canes - there are several types. Those with three (tripod) or four point bases offer considerably more support than the ordinary cane.

Crutches - are familiar to most children, but the type with cuffs or hands that encircle the arm (Kenny sticks) or below the elbow (Canadian crutches) add to security of movement.

Walkers - with or without wheels, are often used to aid mobility and stability in movement.

Braces - mechanical devices made of plastic or metal, not only help facilitate mobility but can also help prevent deformity, hold the body in place, and provide support. Size of braces includes small ones to aid the ankle and long-leg braces that extend from foot to thigh and may have locks and hinges to allow rigidity for standing and flexibility for walking.

Some children who have orthopedic disabilities wear helmets to protect their heads during mobility exercises and other activities.

Wheelchairs - are familiar to most children. They are equipped with seat belts and brakes, and sometimes offer devices like moveable footrests, cup holders, etc. Electric wheelchairs can be operated by pushing a lever with one finger or a hand. Adaptations can be made for use by persons who have quadriplegia and who will need many assistive devices. It is very important to properly measure the child for a wheelchair. The parent and child need clear communication with the vendor, therapist and/or physician.

Young children often like to get around on scooter boards, hand propelled carts, and similar devices.

For classroom and home activities -

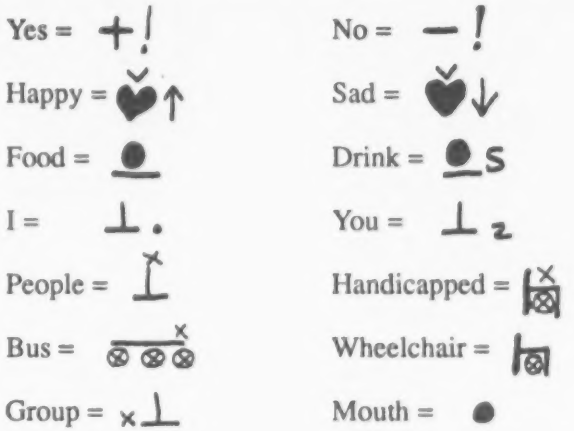
Aids and appliances commonly used include standing frames, adaptive chairs, bolsters and wedges, lowered tables, counters, desks, lap boards, card holders, book and pencil holders, etc.

For self-care -

Many appliances enable persons who are physically disabled to tend to their own needs. Spoons, knives, forks, plates and cups modified in various ways (large, circular tube-like or built-up handles with particular angles; adaptive or lipped edges on plates) make eating easier. Electric appliances such as scissors and toothbrushes; additional railings in showers, bathtubs, and hallways; elevated toilets; and lowered sinks and kitchen appliances, make independence possible. Items such as reachers, velcro fasteners, extra large button holes, and adaptive clothing are important.

For communication -

Devices such as electric typewriters, adaptive telephones, tape recorders, and electronic speech devices expand opportunities. **Computer-assisted communication** or **augmentative/alternative speech devices** are being researched and developed rapidly. For persons without the ability to speak, communication boards such as Touch Talker and Real Voice are two of the many speakers that help users communicate competently. These aids can be programmed simply and then can be stepped up to full, adult vocabulary and technical capacities. They may be accessed by touch, switch, voice or with a laser, light beam on a headband. Most are lap-sized. Some can be hooked up to a computer for word printout. Size, capacity, and prices vary from several hundred dollars up to $5,000.00. **Bliss boards** and other communication boards have printed words or symbols to which the person who is nonverbal can point to or look at to indicate what he or she wants to communicate.
One method of nonverbal communication is called Bliss Symbols. A few examples of words are:



Nicole, a primary grade student who had unintelligible speech, began by pointing to a series of familiar object photographs (grandma, bed, juice, etc.) She then progressed to more abstract line drawings. She used a loaned, augmentative communication device for a year. She no longer needs it, because she can speak without it now. Her mother feels it, along with speech therapy and home reinforcement, aided her receptive and expressive speech considerably.

Questions our puppet with a physical disability has been asked

Why are you in that wheelchair?

> Because my muscles are not as strong as yours, so I can't walk like you do.

Why can't you walk?

Because of my cerebral palsy. When I was born, the part of my brain that controls my muscles was injured. So, it's hard for me to make my legs do what I want them to do. My muscles tighten up and don't work right.

Do you have to sleep in your wheelchair?

No, I sleep in a bed just like you do. I roll my wheelchair up close to the bed and then, with some help from Mom or Dad, I lift myself out of the wheelchair and on to the bed. That's called a "transfer."

How do you take a bath?

Well, Mom helps me into the tub, and I scrub myself as well as I can. Just before I am ready to have her help me out, she checks behind my ears to make sure I'm clean. I love to be in the water 'cuz it helps my muscles relax — you know — like at the swimming pool.

Can you go for a ride in a car?

Sure. Mom, Dad, or a friend helps me into the car seat. Then they collapse my wheelchair and put it in the trunk. Neat, huh! Some day we may get a van, and I'll just roll right in on the ramp. My school bus has a lift.

How do you hold your head still for a dentist?

Before I go to the dentist, I take a muscle relaxant that the doctor ordered for me. Then my head is very relaxed. I'd feel real bad if I accidentally bit the dentist's fingers.

If there were a fire in your house, how would you get out?

The fire department has special signs (decals) that can be put in windows to indicate there is a person who has a disability in the house. My decal is in my bedroom window, so the firemen would know where I'm sleeping.

Can you play any sports?

Sure, there are lots of sports I can play. I love basketball — there are wheelchair basketball teams (like the Minnesota Rolling Gophers). There are square dance groups for people in wheelchairs that I'd like to try out for when I get older. My Dad just found a way to attach a hockey stick to my friend's wheelchair, so he can play floor hockey. I might try that, too.

How do you go up or down stairs?

Well, I always look for ramps or elevators first. If the building doesn't have those, I either stay on the ground floor or someone has to carry me and my wheelchair up or down. Our house is all on one floor, and Dad built ramps for the steps at the front door and back door.

If you can't get your wheelchair up to the drinking fountain, how do you get a drink?

I use a glass. I have a backpack on my wheelchair. In there I keep a glass, tongs or "reachers" to grab things that are out of my reach: sharpened pencils, extra paper, an extra sweater, and my favorite book — you know, in case I have a long wait for my school bus.

Do you have friends?

Oh, yeah, I have lots of friends. Some have disabilities and some don't. Do you have friends who have disabilities and who don't?

Simulation Activities for Physical Disabilities

1. **"MUSCLE CONTROL"** (Elementary)

   EQUIPMENT: Masking tape.

   a. Have children lie down on the floor, then try to get up without using their heads. Discuss the degree of effort required.

   b. Have children sit in a small group while the teacher reads a story or leads a discussion. Have students continually keep dropping their heads loosely, and at the end of the story discuss how well they could follow the story line.

   c. Put a long strip of masking tape on the floor. One at a time, have children close their eyes, spin around several times, open their eyes, and try to walk down the tape line.

2. **"EXTRA WEIGHT"** (Elementary)

   EQUIPMENT: Sandbags with arm bands to go around wrists.

   Put sandbags on wrists and have children walk around the room three times with arms outstretched, or write at a table with sandbags held over the edge. Discuss how difficult it would be to wear heavy braces all the time on arms or legs.

3. **"ALL THUMBS"** (Elementary)

   EQUIPMENT: Masking tape, raisins or chocolate chips, pudding, spoon, heavy socks.

   Tape down the fingers of the weaker hand, leaving only the thumb free. Using only that hand, eat raisins or feed a friend pudding. Discuss their reactions to poor motor control.

   Put a couple pairs of heavy socks on children's hands and have them try the same exercise. Discuss reactions.

4. **"MODES OF MOTION"** (Preschool—elementary)

   EQUIPMENT: Chalk and chalkboard

   Discuss with the children the many ways people move (walking, crawling, hopping, skating, flying, tiptoeing) and why people move in these ways. Then discuss reasons people have for adapting their modes of motion (such as crawling because they're looking for lost contact lenses, tiptoeing because someone is sleeping, running to escape a fire, etc.).

   Have each child choose a "mode of motion" (appropriate for the setting, of course) and use it exclusively for all day or part of a day. Discuss with children their feelings about being able to get around using only one "mode of motion."

5. **"NURSERY RHYMES"** (Preschool — Elementary

   EQUIPMENT: Pictures or books depicting nursery rhymes.

   Discuss various nursery rhymes that the children know and talk about changes that would need to be made if principal characters had certain disabilities.

   Example: JACK AND JILL

   What if Jack's legs didn't work and he used a wheelchair—how would he get a bucket of water from the well at the top of a hill? (Jill could push him up the hill, attach the bucket to the rope, and Jack could lower the bucket into the well by slowly releasing the rope or turning the crank. Also, since Jack was in a wheelchair and Jill would help him down the hill, he wouldn't be likely to fall!)

   Example: HUMPTY DUMPTY

   What if, when he fell off the wall, he broke one of his legs? What could the King's horses and men do for him? Might he be on crutches awhile?

6. **TRY IT OUT** (all ages)

EQUIPMENT: Any aids and appliances that can be secured from rental places or catalogues.

Bring to the classroom devices used by children who have physical disabilities and adults. These can often be rented or borrowed from hospital equipment supply stores or rehabilitation centers. Let the children experiment and ask questions. They might also be interested in looking at catalogues of devices and clothing available for children who have disabilities. PACER Center has an Aids and Appliances Rental Tote which can be rented out for a charge. Contact the COUNT ME IN Program at (612) 827-2966.

This material was reviewed and updated by Maria Anderson, the Early Childhood Coordinator at PACER Center, who is the parent of a daughter who has a disability.

Resources

Books for children

(P = Primary, M = Middle, U = Upper grade level recommendations)

Adams, B. *Like It Is: Facts and Feelings about Handicaps from Kids Who Know.* New York, NY: Walker and Co., 1979. This book is written for school-age children and adolescents. (P, M, U)

Allen, Anne. *Sports for the Handicapped.* New York, NY: Walker, 1981. Stories of real people who have become winners in a variety of adapted sports. Resources listed. (M)

Chaney, Sky; Fisher, Pam, eds. *The Discovery Book.* United Cerebral Palsy of North Bay, Santa Rosa, CA, 1985. Order from UCP, 959 Transport Way, A-1, Petaluma, CA 94952 or call (707) 765-6770. A helpful guide for the world, written by children with disabilities. Chapters on friends, family, feelings, problems, challenges and more.

Exley, H., ed. *What It's Like to Be Me.* New York, NY: Friendship Press, 1984. This book is written and illustrated entirely by children with disabilities. (P, M, U)

Fanshawe, Elizabeth. *Rachel.* Scarsdale, NY: Bradbury Press, 1977. A colorful picture book for very young children about Rachel's life using a wheelchair for mobility.

The Light and Bright Writers' Club. *The Wheelers and the Pushers!* Racine Unified School District, 1700 Youth St., Racine, WI 53404, 1978. A book written by children who use wheelchairs so that "people will understand better how we feel about 'living' in a wheelchair and we could give our friends tips and ideas about how to be a pusher or a wheeler."

Numeroff, Laura Jaffee. *Amy For Short.* New York, NY: MacMillan Publishing Co., 1976. (P, M)

Pursell, Margaret, and Fassler, Maria S. *A Look at Physical Handicaps.* Minneapolis, MN: Lerner Publications, 1976. Black and white photographs and an easy text provide information in a nonfiction picture book for young children. (P, M)

Savitz, Harriett May. *On the Move.* New York, NY: The John Day Co., 1973. A story about young people with paraplegia for whom wheelchair basketball is a means of fun and growing up. (M, U)

Wolf, Bernard. *Don't Feel Sorry for Paul.* Philadelphia, PA: Lippincott, 1974. The story of a boy born with his hands and feet incompletely formed.

Books for adults

Bleck, E.; Nagel, Donald. *Physically Handicapped Children: A Medical Atlas for Teachers.* New York, NY: Grune and Stratton.

Brown, Christy. *My Left Foot.* New York, NY: Simon and Schuster, 1955. The author, able to control only his left foot, writes his autobiography. Now a major motion picture.

Crossley, Rosemary; McDonald, Anne. *Annie's Coming Out.* This famous book is the story of a young Australian woman who was institutionalized with cerebral palsy and the therapist who recognized her communications and assisted her education and ultimate release.

Heilser, Verda. *A Handicapped Child in the Family: A Guide for Parents.* New York, NY: Grune and Stratton, 1972.

Hotte, Eleanor Boettke. *Self-help Clothing for Children Who Have Physical Disabilities.* National Easter Seal Society, 1979. 64 pp. Excellent book for parents describes the need for attractive, specially adapted clothing for children with disabilities, includes bibliography of books and pamphlets as well as a list of commercial catalogs.

Jeter, Katherine F. *These Special Children.* Bull, 1982. Subtitled "The Ostomy Book for Parents of Children with Colostomies, Ileostomies, and Urostomies." Book discusses details of ostomy management, answers to frequently asked questions, and addresses unique parenting needs. Excellent and comforting.

Kovic, Ron. *Born on the Fourth of July.* New York, NY: McGraw-Hill, 1975. Now a movie as well.

Lifchez, Raymond; Winslow, Barbara. *Design for Independent Living: The Environment and Physically Disabled People.* Berkeley, CA: University of California Press, 1981. These very personal profiles of seven men and women from the community of people with physical disabilities in Berkeley, California, where the Independent Living movement began, assess their needs in terms of specific activities such as housing, sleeping, sexuality, grooming, feeding, excreting, gaining accessibility to work and recreation, and eliminating barriers.

Massie, Robert K.; Massie, Suzanne. *Journey.* New York, NY: Alfred Knopf Publishing, 1973. Excellent book about parenting a son who has hemophilia. Both parents are journalists. They write alternate chapters for a very interesting perspective.

Readings in Physically Handicapped Education. Special Learning Corporation, 42 Boston Post Road, Builford, CT 06437.

Robinault, Isabel P., ed. *Functional Aids For The Multiply Handicapped.* Lippincott, 1973. Prepared under the auspices of the United Cerebral Palsy Association, this helpful resource book incorporates information on and pictures of hundreds of functional aids and pieces of equipment. The developmental range from infancy to maturity is covered.

Thompson, Charlotte E. *Raising a Handicapped Child: A Helpful Guide for Parents of the Physically Disabled.* New York, NY: William Morrow, 1986. This powerful and significant book serves initially as a survival guide for parents new to the arena of disabilities or chronic illness and as a problem-solving helper as time goes on.

Weiss, Louise. *Access to the World: A Travel Guide for the Handicapped.* (rev. ed.) New York, NY: Henry Holt, 1986. Chock-full of facts and tips that will make travelling with a disability as easy as possible, *Access to the World* spells out airline policies, bus, train, and ship information, access guides, tour operators, travel agents and travel organizations, hotel and motel accommodations and vacation ideas here and abroad.

Magazines

Sports 'N Spokes. 5201 North 19th Avenue, Suite 111, Phoenix, AZ 80515, (602) 246-9426. Magazine published bimonthly. Articles cover wheelchair competitive sports and recreation primarily for those with spinal cord injury, spina bifida, amputation and some congenital defects.

The Exceptional Parent. 605 Commonwealth Avenue, Boston, MA 02215. This is a consumer magazine for parents of children with

chronic conditions. The magazine is published eight times per year. It contains articles that provide practical information and emotional support for families.

Films

Keep on Walking. (8 min., color, 1972, free) March of Dimes, Box 2000, White Plains, NY 10602. About an 11-year-old boy born without arms who can do amazingly well with his feet.

Get it Together. (color, 1978) A young man who uses a wheelchair because of an auto accident is a recreation therapist and shows how people with orthopedic impairments can be active in sports. Available from Advocacy for Handicapped Citizens, Inc., 111 Church St., Charleston, SC 29401.

He's Not the Walking Kind. Pilot Club International (29 min., sound, 16mm). Story of a young man who refuses to let a physical disability cut him off from life. His family helps him achieve confidence and independence. Junior high age level and above.

There's More to Me Than What You See. (28 min., color, 1981) Augsburg Publishing House, Audi visual Dept., 426 S. 5th St., Box 1209, Minneapolis, MN 55440, (612) 330-3552. The film features two adults who are physically disabled and the parent of a child with multiple disabilities discussing people's attitudes towards disabilities.

The Same Inside. (13 min. color, 16mm, 3/4" video, 1/2" video) 1983. Four children with birth defects share their feelings, fears and dreams in the sensitive award winning film. Available from March of Dimes, 4940 Viking Drive, Suite 268, Edina, MN 55435, 835-3033.

You Can. (28 min., color, sound, 16mm) Illustrated, high-ability program for students with physical disabilities. This enrichment program allows students to participate in activities beyond the scope of their high school setting, studying marine and marsh life, and visiting the Marine Science Institution at the College of William and Mary. National Oceanic and Atmospheri Administration.

Additional films are listed in the Additional Resource Section at the end of the manual.

Organizations

National organizations include:

National Easter Seal Society
70 East Lake Street
Chicago, IL 60601
(312) 726-6200

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
(914) 428-7100

Muscular Dystrophy Association
810 7th Avenue
New York, NY 10019
(212) 586-0808

United Cerebral Palsy Association
7 Penn Plaza, Suite 804
New York, NY 10001
(212) 481-6300

National Multiple Sclerosis Society
205 East 42nd Street
New York, NY 10017
Toll free: 1-800-637-6303
(212) 986-3240

Spina Bifida Association of America
1700 Rockville Pike, Suite 540
Rockville, MD 20852
Toll free: 1-800-621-3141
(301) 770-7222

National Spinal Cord Injury Association
369 Elliot Street
Newton Upper Falls, MA 02164

State organizations and agencies are listed in Additional Resource Section at the end of the manual.

Mental Retardation

What is mental retardation?

P. L. 94-142 defines mental retardation as "significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period, which adversely affects a child's educational performance."

Analyzing this definition sheds light on some of the controversies in the field of mental retardation. **Subaverage intellectual functioning** refers to scoring two or more standard deviations below the mean on an intelligence test. **Adaptive behavior** refers to learned skills including social, self-help, academic and vocational. For many years, only intellectual function and not adaptive behavior was considered in labeling persons as having retardation, despite the fact that many of them functioned well outside of school settings.

Basically, the definitions above clearly state that a person who has mental retardation is one whose mental growth and social development are low compared to the average growth of most people.

According to the 1989-90 Minnesota Special Education Child Count, 10,338 children with mild-moderate to severe-profound retardation were receiving special education services. This includes children from birth to age 21. These children differ from each other in the same way that all people have unique differences. Most cannot be identified by physical characteristics.

Certain common characteristics do exist. Persons who have mental retardation all have difficulty in learning and applying knowledge. It takes them a longer time to learn how to do most of the things that are easy for other people. Learning does take place in the same general order as for normal children but at a much slower rate.

The degree of retardation may vary from mild to profound.

Persons with mild retardation differ from their normal peers primarily in the rate and degree of their intellectual development. Mild retardation may not become apparent until a child enters school. It has been estimated that over 90% of mental retardation falls within this level. (Usually an IQ score of 50-75 combined with some deficits in adaptive behavior). Many people with mental retardation can achieve social and vocational skills necessary for self-support. Others need guidance or support when they are under social or economic distress.

Persons with moderate retardation (below 50 I.Q. level) can usually learn to take care of their personal needs and perform vocational tasks.

Persons with severe retardation can usually learn basic self-care and perform economic tasks with supervision.

Persons with profound retardation may be primarily dependent on others for their care, but some people can achieve limited self-care.

School districts have special services for students who have mental retardation. Some schools identify persons who are mildly retarded as **educably mentally retarded** and identify others who have lower abilities as **trainably mentally retarded**. Many students who have educable mental retardation (EMR) spend most of each school day with a regular class and receive special education services for a portion of their day.

In many school districts throughout the nation children with severe retardation are receiving their special education services in regular classrooms. Models for educating children with retardation have shifted dramatically from segregated settings to integrated services.

The following characteristics are ones that occur more often in children who have mental retardation than in peers of normal ability. It is not likely that all of these will occur in any one child, but some

combination of these characteristics is found in most children who have mild mental retardation:

- sensory and motor coordination disabilities
- low tolerance for frustration
- poor self-concept
- short attention span
- below average language ability
- below average ability to generalize and conceptualize
- play interests younger than those of peers

Causes of mental retardation

Mental retardation can result from infectious diseases, abnormalities of gestation, dietary deficiencies, metabolic disorders, blood type incompatibility, environmental influence and many other factors. Although there is no conclusive evidence, many authorities believe that a majority of persons have mild retardation because of early cultural and social disadvantages. One form of retardation is Down syndrome. This is the most common form of mental retardation. Down syndrome is a genetic disorder caused either by an extra chromosome or piece of chromosome in the genetic makeup. There are three major types. **Trisomy 21** is the most common and is due to failure of one pair of genes to separate at conception resulting in the addition of an extra chromosome. **Mosaicism**, which usually results after conception, is the presence of an extra chromosome in only part of the cells. **Translocation** occurs when a chromosome becomes attached to another and causes an excess of material on one chromosome. There is no known reason for any of these to occur. Prevention and prediction are impossible with the exception of some carriers of the translocation type. Statistically, the rate of Down syndrome rises with maternal age.

At one time it was thought that all persons with Down syndrome were severely to profoundly retarded. This is now known not to be the case. The level of intelligence usually ranges from moderate to severe retardation. Some individuals with Down syndrome, however, function at a mildly handicapped level. Thus, no one can predict what the newborn can or cannot accomplish. The only certainty is that the child with Down syndrome will be slower to learn and to develop than other children without this disability. It is important to remember that the child with Down syndrome is more like the normal child than he is different.

In the past, the educational needs of children with Down syndrome were unmet or met by isolating them in various segregated classes. Today, the idea of normalization is directed toward the social, physical, and educational integration of the individual into the mainstream of school and society.

There are over 250 known causes of mental retardation. Nevertheless, many persons have retardation where the cause is unknown. Most people with retardation are not physically distinguishable from the general population. There are other known disorders that may accompany mental retardation such as, Fragile X syndrome, Rett's syndrome, Williams syndrome or Prader-Willi syndrome.

Some questions and controversies

Several court suits have been brought on behalf of children who were placed in classes for students with mental retardation and who were not properly diagnosed. Some had been mislabeled due to inappropriate or biased tests (e.g., not in child's primary language) or insufficient data (e.g., hearing impairment not considered).

These suits have raised questions about procedures for identification and placement of students who have mental retardation. Care must be taken to assure that all measures used for assessment are appropriate and comprehensive for the child.

In the past, I.Q. scores were sometimes the only criteria used to determine mental retardation and were considered a permanent measure. However, there are indications now that I.Q., in some cases, can be increased.

Feelings about mental retardation

In the book, *Feeling Free*, one of the boys talks about his brother who has mental retardation.

> Most people think that someone who's retarded can't do anything by himself, but Brian likes to do a lot of things on his own.

He likes to ride his bike and he loves to swim. He also loves just to take a walk and to see people that he knows. And he's learning more about how to take care of plants than anybody I know.

Some people ask me what it's like to have a brother who's retarded, and I really don't know how to answer that. Kids that are retarded don't all look alike or have the same problems as Brian. Each person has his or her own problems and his or her way of acting. Just like Brian does. To me, he's just a fun kid to have around. He's not a brother who's retarded; he is just Brian. I don't think about him any other way. *

* Reprinted from *Feeling Free*, © 1979, American Institute for Research by permission of Addison-Wesley Publishing Company, Inc., Reading, MA 01867. All rights reserved.

Puppet used to portray mental retardation

The puppet, Corky, has mental retardation and is the same age as the other puppets. He attends a regular school and has art, music and physical education classes with his peers. He is in a special education classroom for some of the day. He has participated in the Special Olympics and likes to play baseball. He expresses concern about the fact that kids tease him, which hurts his feelings.

Questions asked about mental retardation

How many people have mental retardation?

Approximately 3% of the total population have mental retardation (about 120,000 Minnesotans).

What are the levels of mental retardation?

Mild, moderate, severe, and profound retardation. About 90% of all people with mental retardation are only mildly affected and are, in many respects, quite similar to people without mental retardation.

What is the difference between mental retardation and mental illness?

Mental retardation is a developmental disability which is a severe, chronic disability of a person which (a) is attributed to a mental or physical impairment; (b) happens prior to age 22; (c) is likely to continue indefinitely; and (d) results in substantial functional limitations.

Mental illness is a condition exhibiting one or more of the following characteristics that over a long period of time and to a marked degree, adversely affects performance: (a) an inability to learn which cannot be explained by intellectual, sensory, or health factors; (b) an inability to build or maintain satisfactory interpersonal relationships with peers; (c) inappropriate types of behavior in feelings under normal circumstances; (d) a general, pervasive mood of unhappiness or depression; or (e) a tendency to develop physical symptoms of fears associated with personal or professional problems.

Simulation activities on retardation

1. **"WRITING"**

EQUIPMENT: Pencil, paper.

Children with mental retardation work very hard at learning things. This experiment illustrates how hard persons who have retardation work at writing. Ask each of the children to write a sentence on any subject—but every word in the sentence must have two syllables. Discuss whether this was hard. What if they had to work this hard to learn everything?

2. **"DIRECTIONS"**

EQUIPMENT: None.

Explain that many children who have mental retardation have a hard time learning to follow

even a few simple directions. Have the children stand. Tell them the teacher is going to read them a list of directions and then they are to repeat them in order. Give 10-15 directions rapidly (e.g., stand, sit, clap twice, touch your head, touch your knee, jump, etc.).

Perhaps only a few children should try this while the other watch. Talk with the children about how even a few simple directions may seem this hard to a child with mental retardation.*

* Barnes, Berrigan, and Biklen. *What's the Difference?* Syracuse, NY: Human Policy Press. 1978. Page 41

3. **"PIRATES SEARCH FOR TREASURE"**

EQUIPMENT: Paper, crayons, pencils.

Some children with mental retardation cannot read at all. Discuss what difficulties that would present in playing some games. Have the children pretend that they are pirates and need to follow a map to find a treasure. One of their friends who will participate is mentally retarded and can't read. How could they make the map so everyone could read it?

4. **"MITTEN GAME"**

EQUIPMENT: Mittens or tape and puzzles.

Some people with mental retardation have trouble making their fingers do what they want them to do. Have several children put on mittens or tape some of their fingers together and try to do a puzzle.

This information on mental retardation was reviewed and updated by Karen Grykiewicz, ARC of Minnesota, and Marge Goldberg, co-director of PACER Center.

Resources

Books for children

(P = Primary, M = Middle, U = Upper grade level recommendations)

Brightman, Alan. *Like Me.* Boston, MA: Little, Brown and Co., 1976. Photographs and poems designed to bring the word "retarded" into open discussion among grade school children. (P, M, U)

Buchbinder, Debra. *Special Kids Make Special Friends.* Shalom Association for Children with Down syndrome, 1984. Excellent photos and simple text describe children in a preschool setting emphasizing similarities and strengths rather than differences. (P, M)

Byars, Betsy. *The Summer of the Swans.* New York, NY: Viking Press, 1970. A beautifully written story about 14-year-old Sara and the interrelationships within her family, which includes Charlie, a brother with retardation.

Cairo, Shelley. *Our Brother Has Down Syndrome.* Annick Press Ltd., 1985. Simple text and charming color photos grace this introduction for children.

Carpelan, Bo. *Bow Island.* New York, NY: Delacorte Press, 1971. An 11-year-old boy with retardation goes on a summer holiday. He is gentle, in tune with nature, and has much to give.

Cleaver, Vera; Cleaver Bill. *Me Too.* Philadelphia, PA: J.B. Lippincott, 1974. The Cleaver family includes twins, one of whom has retardation. (U)

Fassler, Joan. *One Little Girl.* New York, NY: Behavioral Publications, 1971. Although she has mental retardation, Laurie learns that she is only slow in some things.

Forrai, Maria; Anders, Rebecca. *A Look at Mental Retardation.* Minneapolis, MN: Lerner Publications Co., 1976. Easy to read text and sensitive pictures. (M, U)

Friis-Baastad, Babbis. *Don't Take Teddy.* New York, NY: Scribner and Sons, 1967. Teddy, who has mental retardation, accidentally hurts someone; his brother, Mikkel, runs away with him. Dynamics of family living are dealt with great honesty and insight. (U)

Glazzard, Margaret H. *Meet Lance, He's a Special Person.* Lawrence, KS: H and H Enterprises, 1978. This book presents a clear, positive picture of a class of children who have mental retardation, with a focus on Lance, who has Down syndrome. Excellent. (P)

Grollman, Sharon Hya. *More Time to Grow.* Boston, MA: Beacon Press, 1977. This book is intended for use with children to explain mental retardation. First section is a story, followed by questions to think about and activities for children to reinforce the message about retardation. (P, M)

Hasler, Eveline. *Martin is Our Friend.* Abingdon Press, 1981. Easy-reading story of a boy with Down syndrome who gains understanding and respect of other children by learning to ride a horse.

Jansen, Larry. *My Sister Is Special.* Standard Publishing Co., 1984. A "Happy Day Book" with simple text about understanding a preschooler with Down syndrome as told by her young brother.

Klein, Gerda. *The Blue Rose.* New York, NY: Holt, Rinehart and Winston, 1975. Jenny is different from others and needs more love and affection. (M, U)

Larsen, Hanne. *Don't Forget Tom.* London, England: A and C. Black, 1974. Daily life of a six-year-old boy with mental retardation. Clear text, excellent color photographs. Honest and helpful book for young readers. (P, M)

Litchfield, Ada. *Making Room for Uncle Joe.* New York, NY: A. Whitman, 1984. Uncle Joe has Down syndrome and comes to live temporarily with his sister's family. Nephew Don describes the family's apprehensions and their adjustment to this new stress. Joe becomes a part of this family. (P, M)

Little, Jean. *Take Wing.* Boston, MA: Little, Brown, 1978. Laurel feels responsible for her little brother James, who is slow to learn and socially dependent. Story contains many elements found in the lives of siblings who live with a brother or sister who is retarded. (P, M)

Meyer, Robert. *Like Normal People.* New York, NY: McGraw-Hill, 1978. The book describes the growing up years of the author's brother, who had retardation. A well-written look at the past. (M, U)

Olminsky, Elaine. *Jon O., A Special Boy.* New Jersey: Prentice-Hall, Inc., 1977. Photo essay of a child with Down syndrome, at home and at play. (P, M)

Perske, Robert. *Show Me No Mercy.* Abingdon Press, 1984. Perske's first teen novel is about a 16-year-old twin with Down syndrome. (U)

Rabe, Berniece. *Where's Chimpy?* New York, NY: A. Whitman, 1988.

Rodowski, Colby F. *What About Me?* Franklin Watts, 1976. A frank, honest account of the difficulties of 15-year-old Dorrie whose younger brother has Down syndrome. Clearly delineates the negative feelings that siblings of a child with retardation may experience. (M, U)

Sheldon, Mary. *The Summer Friend: Special Stories for Special Children.* Audio-cassette with 15 stories read by notable performers such as Julie Andrews, Elliot Gould, etc. (1 hour, 16 min.)

Sobol, Harriet Langsam. *My Brother Steven Is Retarded.* New York, NY: MacMillan Co., 1977. Eleven-year-old Beth talks about her brother, Steven, who has been brain injured since birth. The book's focus is on Beth and her feelings. (P, M)

Wrightson, Patricia. *A Racehorse for Andy.* New York, NY: Harcourt, Brace, 1968. Andy's retardation gradually separates him from the

boys he has grown up with in Sydney. Well-written story with a positive presentation of a boy who has mental retardation. (M)

Books for adults

Baker, Bruce L.; Brightman, Alan J.; Heifetz, Louis J.; Murphy, Diane M. *Behavior Problems*. Illinois: Research Press, 1976.

Blatt, Burton. *The Conquest of Mental Retardation*. Austin, TX: PRO-ED Publishers, 1987. Highly recommended as the most important book on the subject.

Dougan, Terrell; Isbell, Lyn; Vyas, Patricia. *We Have Been There*. Abingdon, 1982. Guidebook for parents is a compilation of personal accounts: laws, concerns of siblings, organizations, the service system, and feelings.

Hall, Lynn. *Sticks and Stones*. Chicago, IL: Follet, 1972. A boy with mild retardation spreads rumors about another boy who rejected his friendship.

Hunt, Nigel. *The World of Nigel Hunt: The Diary of a Mongoloid Youth*. Garrett Publications, 1967. An autobiographical essay written by a man with Down syndrome.

Hutt, Max L.; Gibby, Robert Gwyn. *The Mentally Retarded Child, Development, Education and Treatment*. (3rd ed.) Boston, MA: Allyn and Bacon, 1976.

Janes, Diane ed. *Jamie*. Livonia Public Schools, 1980. A 17-year-old student who has mental retardation compiled this booklet. Teacher and parents add their comments in this remarkable collection.

Kanat, Julie. *Bittersweet Baby*. 1987. An account of the experiences and feelings of the author, the mother of a baby with Down syndrome.

Koch, Richard; Koch, Kathryn. *Understanding the Mentally Retarded Child: A New Approach*. New York, NY: Random House, 1975. Information and the need for advocacy.

Meyers, Robert. *Like Normal People*. New York, NY: McGraw Hill, 1978.

Pader, Olga F. *Guide and Handbook for Parents of Mentally Retarded Children*. Charles C. Thomas, 1981. Information about development and capabilities of children who are mentally retarded, how to teach appropriate behaviors, etc. Book grew out of a course outline for parent groups.

Patterson, Gerald R.; Gullion, M. Elizabeth. *Living With Children*. (revised ed) Illinois: Research Press, 1968.

Perske, Robert. *Circles of Friends*. People with disabilities and their friends enrich the life of one another. Nashville, TN: Abingdon Press, 1988.

Perske, Robert. *Hope For Families: New Directions for Parents of Persons With Retardation or Other Disabilities*. Nashville, TN: Abingdon Press, 1976.

Perske, Robert. *New Life in the Neighborhood: How Persons With Retardation and Other Disabilities Can Help Make a Good Community Better*. Nashville, TN: Abingdon Press, 1980.

Robinson, Nancy M.; Robinson, Halbert B. *The Mentally Retarded Child*. (2nd ed.) New York, NY: McGraw-Hill, 1976.

Strauss, Susan. *Is It Well with the Child? A Parent's Guide to Raising a Mentally Handicapped Child*. Doubleday and Co., 1975. It is worth reading for parents and professionals and is written by a parent.

Stray-Gunderson, Karen. *Babies with Down Syndrome. A New Parents' Guide*. Woodbine House, 1986. Highly recommended book with chapters by both parents and professionals.

Films

Films with an * are available from University Film and Video, Suite 108, 1313-5th Street SE, Minneapolis, MN 55414; (612) 627-4270.

All My Buttons. (28 min., color, sound.) Available from Audio-Visual Center, University of Kansas, 746 Massachusetts, Lawrence, KS 66044. Deals with the problems in the normalization of citizens with developmental disabilities.

Board and Care. * (27 min., color, sound, 1980) Produced by Ron Ellis, Pyramid Films. This is a sensitive story about the desires of two teenagers with Down syndrome for a meaningful relationship, but how circumstances thwart their friendship.

David: Portrait of a Retarded Youth. * (28 min., color, sound) David McFarlane, born with Down syndrome, is now a 17-year-old young man who just finished an assignment to play the lead in a TV drama about retardation. He talks freely about his disability. He's determined to master new situations and inspires those around him.

Flowers in the Sand. * (28 min., 16mm, color, sound) Daniel is in his twenties and has mild retardation. Film is about his struggle to become independent.

Gifts of Love. (25 min., color, sound.) 3/4 or 1/2 inch videotape, available from National Down Syndrome Society (NDSS). Telephone: 1-800-221-4602. Four families of children with Down syndrome talk about their experiences with their child with disabilities, particularly during the first six years.

It's Harder for Patrick. (7 min., 16mm, color, sound) from ZOOM Series. Love and understanding help the Reardon family cope with Patrick, their son who has retardation and his brother.

James and John. (23 min., color, sound, 1973.) Available from Peach Enterprises, 4649 Gerald, Warren, MI 48092. Twin boys with Down syndrome are members of a loving family who help them grow comfortably in the community.

Let Me Try. * (7 min., color, sound, 1977.) Produced by Alan P. Sloan, Avator Learning, Inc./Encyclopedia Britannica. Billy brings his sister with mental retardation along to a friend's house to help build a tree house, but grandmother does not think it's safe to allow the little girl outside with others.

Paige. * (Down syndrome) (10 min., 16mm, color, sound) from People You'd Like to Know Series. The film traces the different activities of a typical day of 11-year-old Paige who has Down syndrome. Her younger sister shares her feelings and wishes for her sister Paige.

Try Another Way. (27 min.) Available from Film Productions of Indianapolis, 128 E. 36th St., Indianapolis, IN 46205. Introduction to the techniques of Dr. Marc Gold, demonstrating the competence of people who have retardation.

Who's Handicapped? (34 min., color.) Available from Insight Exchange, P.O. Box 42585, San Francisco, CA 94101. A British documentary film showing three approaches for helping children with mental retardation and emotional disorders to become included in a class where children with and without disabilities learn from each other.

See Additional Resources Section at the end of the manual.

Organizations

National organizations include:

American Association of University Affiliated Programs for Persons with Developmental Disabilities
605 Cameron Street, Suite 406
Silver Springs, MD 20910
(301) 588-8252

Association of Retarded Citizens of the U.S.
2501 Avenue J
Arlington, TX 76006
(817) 640-0204

National Down Syndrome Congress
1800 Dempster Street
Park Ridge, IL 60068-1146
(312) 823-7550
Toll free: 1-800-232-6372

National Down Syndrome Society (NDSS)
666 Broadway
New York, NY 10012
(212) 460-9330
1-800-221-4602

Nonaversive Behavior Management Information and Referral Service

National Research and Training Center on Community-Referenced, Non-aversive Behavior Management for Students with Severe Disabilities
San Francisco State University
San Francisco, CA 94132
1-800-451-0608 (9 A.M. to 4 P.M. Pacific Time)

National Fragile X Foundation
1441 York Street, Suite 215
Denver, CO 80206
(303) 333-6155
1-800-688-8765

International Rett Syndrome Association
8511 Rose Marie Drive
Fort Washington, MD 20744
(301) 248-7031

The Association for Persons with Severe Handicaps (TASH)
7010 Roosevelt Way NE
Seattle, WA 98115
(206) 523-8446

The Joseph P. Kennedy Jr. Foundation
1701 K St. NW
Washington, DC 20006

Tourette Syndrome Association
4240 Bell Boulevard
Bayside, NY 11361

State organizations and agencies are listed in Additional Resources Section at the end the manual.

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Learning Disabilities

What are learning disabilities?

In Minnesota, 32,994 children (ages birth to 21) were identified as having specific learning disabilities and were receiving special education services during the 1989-90 school year.

According to P.L. 94-142, "learning disabilities" is "a disorder in one or more of the basic psychological processes involved in understanding and using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, spell or to do mathematical calculations."

The National Advisory Committee on Handicapped Children, U.S. Office of Education, adds the following to the definition of learning disabilities: "Learning Disabilities include conditions which have been referred to as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, developmental aphasia, etc. They do not include learning problems which are due primarily to visual, hearing or motor disabilities, to mental retardation, emotional disturbance or to environmental disadvantage."

In 1984, the Association for Children and Adults with Learning Disabilities adopted a definition which stresses the potential of learning disabilities for affecting people throughout their lives:

Specific learning disabilities is a chronic condition of presumed neurological origin which selectively interferes with the development, integration, and/or demonstration of verbal and/or non-verbal abilities. Specific learning disabilities exists as a distinct disabling condition in the presence of average to superior intelligence, adequate sensory and motor systems, and adequate learning opportunities. The condition varies in its manifestations and in degree of severity. Throughout life the condition can affect self-esteem, education, vocation, socialization, and/or daily living activities.

Most children with learning disabilities are average or above average in intelligence but there is severe discrepancy between achievement and intellectual ability in one or more of the academic areas. Modifications in teaching methods should be utilized in the classroom. Some modifications to help the student with learning disabilities would be to provide him/her with a designated note-taker, untimed testing, reduced written assignments, and modified curriculum. Children with learning disabilities may have problems learning to read, write, spell, compute, or listen. They may also have difficulty expressing their thoughts verbally or in writing.

Some of the specific disorders which are considered learning disabilities are listed below:

Dyslexia - Basically, this word means difficulty with learning to read. It may involve several different factors including reversals, substitutions, confusion of symbolic meanings and others.

Dysgraphia - Trouble in learning to write, including spelling difficulties.

Dyscalcula - Difficulty with mathematics.

Perceptual disorders - A message from one of the senses is not received and/or interpreted properly by the brain. A ***visual perception disorder*** means that results might include reversals or an inability to distinguish the difference in shapes. ***Auditory perception disorders*** include problems in discriminating words, comparing them with other sounds, and making the sound blendings so essential to learning to read. Auditory perception difficulties may be a factor in spoken language problems. Often children with perceptual disorders do not grasp the entire meaning of a spoken or written message. They may not pick up facial expressions or body language.

There are some characteristics that seem to be displayed more frequently by children with learning disabilities than by other children. No one child will show all of these characteristics; but the fol-

lowing list may provide some examples of behaviors and some clues for identifying children with learning disabilities:

Attention deficit disorders - Child moves nearly all the time and has trouble attending to a specific task. They exhibit distractibility and impulsivity. Learning disabilities and attention deficit-hyperactivity disorder (ADHD) are related and often found together but they are **separate** conditions. This condition was formerly called hyperkinetic syndrome of childhood or hyperactivity.

Hypoactivity - Child is abnormally inactive.

Lack of coordination

Perseveration - Child persistently repeats actions or words.

Inattention

Language problems

Overattention - Child focuses inordinately on one particular object.

Perceptual disorders

Memory disorders

Uneven skill levels in different areas

One characteristic is common to all children with learning disabilities: a significant educational discrepancy between expected achievement (ability, potential) and actual achievement.

Educational methods

It is very important for students with learning disabilities to be identified and tested in order to determine the specific areas in which the student is experiencing difficulty. A comprehensive assessment helps to identify the learning problems that are causing the severe discrepancy between potential and achievement. Specially trained teachers can provide different types of help depending on the child's needs. Sometimes, special materials for the child and consultation with the classroom teacher will work well. In other situations, a child will benefit from receiving special help individually or in a small group from a resource teacher each school day. The majority of students with learning disabilities in Minnesota receive this type of resource assistance. In some cases, learning disabled students spend most of their school day in a special classroom setting.

There are many materials available to help students learn to either compensate for their disorder or learn in other ways.

Many famous people were learning disabled — Albert Einstein, Winston Churchill, and Woodrow Wilson, to name just a few. The singer Cher, actor Tom Cruise and Olympic star Bruce Jenner are three who have been successful in their fields. Thomas Alva Edison had a difficult time learning to read and write. He wrote the following letter to his mother at age 19:

> *Dear Mother — started the store several weeks. I have growed considerably I don't look much like a boy now — hows all the folk did you receive a box of books from Memphis that he promised to sent them — languages. Your son Al.*

Feelings about learning disabilities

The child who expressed these feelings so well happens to be part of the cast of the television series "Feeling Free," and whose words were published in the book, *Feeling Free.*

> Learning new things can be really exciting if you get into them a lot and really work at them. That's what rock climbing and skateboarding were like for me. When I learn something new I just get really excited, and I keep doing it over and over again. But learning has not always been an easy thing for me.
>
> School is probably the best example of something that has been really hard for me, almost all the time. When the other kids were going outside for recess, I would always have to stay inside to do extra work or to finish stuff that I was having trouble

with. For me that meant reading, spelling, and writing most of all.

I could do just about anything else, but those three things were real problems for me. It seemed like everyone else could breeze right through them, but I'd always get stuck.

It took me a while to understand that I had specific learning problems.

Puppet used to portray learning disabilities

Mitch has a hidden disability. He has learning disabilities. He has trouble reading, writing and remembering his spelling words. He tries hard, but he gets frustrated easily. He needs to find other ways to learn and be tested. He feels so badly when he cannot do well. He has many abilities, however. He is very coordinated and loves sports. He knows a lot about bikes and races them. He is captain of the baseball team and is in several scripts besides learning disabilities.

Questions most frequently asked about persons with learning disabilities

Can people with learning disabilities learn?

Absolutely, although they may learn in different ways from other children. People with learning disabilities have average or better intelligence. They can succeed.

Do learning disabilities go away as a person grows up?

No, but with appropriate help, many adults have learned to cope very well. There are many successful adults in many fields of work and professions.

How can you tell if a person is learning disabled?

Because a learning disability is a hidden disability, there are no clearly visible indicators. A thorough, comprehensive assessment by a team is needed.

Simulation activities for learning disabilities

1. **"READING PUZZLE"**

EQUIPMENT: Pencil and paper.

Some children with learning disabilities have a hard time telling one letter from another.

Make up 10 symbols for words the children can read. Show them the list of symbols along with the corresponding word and give them only a minute or two to study it. Then show the children the symbols in a different order and ask them to write the correct word next to each symbol. Make them hurry.

Talk about how the difficulties they experience may be what it is like for some children learning to read. Ask them how they felt and what would have made it easier for them to learn the symbols. Relate their answers to how people with learning problems need other ways to learn things.

2. **"WHAT WAS THE PAGE?"**

EQUIPMENT: Book, pencil and paper.

This activity also shows how learning disabled students need activities adjusted. It emphasizes how a child might feel.

Tell the children you are going to pretend for a while. Then very abruptly give them the wrong page for an assignment—one too difficult for them. Tell them not to bother you for help as you are busy. Discuss how they feel after the play-acting is finished.

3. **"CRAZY WRITING"**

EQUIPMENT: Mirrors, pencils, paper.

To many children with learning disabilities, letters do not appear the same as they do to most people.

Have the children work in pairs. Have one child write a message and tape it to his partner's forehead. That child must try to read it in the mirror.

For another experience, have them try writing a sentence with their non-dominant hand.

This material on learning disabilities was reviewed and updated by Barbara B. Sorum, former Advocacy and Education Manager, Learning Disabilities of Minnesota; current Parent Advocate, PACER Center, Inc.

Resources

Books for children

(P = Primary, M = Middle, U = Upper grade level recommendations)

Albert, Louise. *But I'm Ready to Go.* Scarsdale, NY: Bradbury Press, 1976. Story of a 15-year-old, Judy Miller, who has learning disabilities. (M, U)

Bever, Shirley. *Good For Me. Adolescent Training.* Student guidebook and leader manual. M.A.C.L.D. 1984.

Cleary, Beverly. *Mitch and Amy.* NY: Morrow/Morrow, Jr., 1967. Mitch's school problems are typical of L.D. Some of them are partially remedied by his twin sister, Amy. (M, U)

Gillham, Bill. *My Brother Barry.* Andre Deutsch, 1981.

Hayes, Marvell. *The Tuned In-Tuned On Book About Learning Problems.* Academic Therapy Publications, Novato, CA: 1974. About children with learning disabilities, written for children with learning disabilities (parents and teachers can read it, too!).

Hipp, Earl. *Fighting Invisible Tigers.* Mpls., MN: Free Spirit Publishing Co., 1985. Helpful strategies for dealing with emotional stress for teens, especially gifted.

Janover, C. *Josh: A Boy with Dyslexia.* Bowling Green, OH: Waterfront Books, 1988.

Jensen, Eric. *Student Success Secrets.* New York, NY: Barron's Educational Series, Inc., 1982. This book shares study skills, includes whole mind learning techniques.

Lasker, Joe. *He's My Brother.* Chicago, IL: Albert Whitman, 1974. The book tells about the life of a child with learning disabilities and his family. (M, U)

Levine, Melvin. *Keeping Ahead in School: A Student's Book About Learning Abilities and Learning Disorders.* Educator's Publishing Services, Inc., 75 Moulton Street, Cambridge, MA 02138-1104, (617) 547-6706,1990. Positive approach to compensate for and to overcome learning disabilities. Book $14.50 or six audio cassette tapes for $24.50. (M, U)

Meyer, Donald J.; Vadasy, Patricia F.; Fewell, Rebecca R. *Living with a Brother or Sister with Special Needs: A Workbook for Sibs.* University of Washington Press, 1985.

Mortiar, Ahmed. *I Am Not Dumb.* Zan Press, 1979. (M)

Pevsner, Stella. *Keep Stompin' Till the Music Stops.* Boston, MA: Houghton Mifflin Co., 1977. Deals with shared problems of a young boy with a learning disability and his great-grandfather whose children don't endorse his independent philosophy.

Smith, Doris Buchanan. *Kelly's Creek.* NY: Crowell, 1975. Story of a nine-year-old boy with motor and perceptual problems and how he gains self-confidence through his interest in a Georgia marsh. (M, U)

Swenson, J.; Kunz, R. *Learning My Way, I'm a Winner.* Minneapolis, MN: Dillon Press, 1986. Non-fiction.

Books for adults

Barkley, R. *Hyperactive Children.* New York, NY: Guilford Press, 1981.

Behrmann, Polly. *Why Me?* Available from the author (840 Seabrooke Court, Englewood, FL 34223), 1990. The adolescent and young adult with learning disabilities faces many problems of disorganization, clumsiness and insecurity when dealing with everyday situations. The author has isolated some common situations and gives suggestions for teaching social skills, memory skills and math skills.

Bever, Shirley. *Building Your Child's Self-Image, A Guide for Parents.* Minnesota Association for Children and Adults with Learning Disabilities, 1978.

Brutten, S. Richardson; Mangel, C. *Something's Wrong with My Child.* New York, NY: Harcourt, Brace, 1973. For parents and other concerned lay persons. This book describes how to recognize the child with learning disabilities and where to go for help.

Chalfant, James; Kirk, Samuel. *Academics and Developmental Learning Disabilities.* Love Publishing Co., 1985.

Clarke, Louise. *Can't Read Can't Write Can't Talk Too Good Either: How to Recognize Dyslexia in Your Child.* Walker, 1973. Mike had an IQ of 138 but was unable to read or write. This book describes the therapies that proved successful in overcoming his disability.

Directory of Facilities and Services for Learning Disabled. (9th ed. 1981/82), Academic Therapy Publishers, 20 Commercial Blvd., Novato, CA 94947.

Edge, Denzil; Strenecky, Bernard J.; Mour, Stanley I. *Parenting Learning-Problem Children: The Professional Educator's Perspective.* Ohio State University Press, 1978. Written by and for professional educators, this book is a welcome sign of the acceptance by professionals of the importance of parents as teachers, as agents of change, as lobbyists for better services, and as monitors of their own children's programs and welfare. The book outlines legitimate roles for parents in solving typical problems arising in the education of their children with learning disabilities.

Fuldisged, P.M. *A Guide to Post-Secondary Education Opportunities for the Learning Disabled, A National Directory of Four-Year Colleges, Two-Year Colleges, and Post-High School Training Programs for Young People with Learning Disabilities.* (4th ed.) Tulsa, OK: Partners in Publishing, P.O. Box 50347, 1981.

Gordon, T. *P.E.T. Parent Effectiveness Training.* North American Library, 1975.

Greene, Lawrence J. *Learning Disabilities and Your Child.* New York, NY: Fawcett Columbine, 1987. Greene explains every possible issue related to learning disorders and presents a series of case studies.

Kronick, Doreen. *They Too Can Succeed: A Practical Guide for Parents of Learning Disabled Children.* San Rafael, CA: Academic Therapy Publishers, 1973.

Levine, Melvin. *Developmental Behavioral Pediatrics.* Philadelphia, PA: Saunders College Pub., 1983.

Levy, Harold B. *Square Pegs, Round Holes.* Boston, MA: Little, Brown and Co., 1973. A practicing pediatrician takes a sensitive and sensible look at the child who has learning disabilities and what can be done to help him.

Lyman, Donald E. *Making the Words Stand Still.* Boston, MA: Houghton Mifflin Co., 1986. A master teacher tells how to overcome specific learning disability, dyslexia and old-fashioned word blindness.

Mangrum II, Charles T.; Strichart, Stephen. *Peterson's Guide to College with Programs for Learning Disabled Students, 1988.* Most complete guide to over 900 four-year and two-year colleges with programs and services for students with learning disabilities.

McWhirter, J. Jeffries. *The Learning Disabled Child: A School and Family Concern.* Lanham, MD: University Press of America, 1988. A psychologist who is also the parent of two sons with learning disabilities has written this very practical guide.

Moss, Robert A. with Helen Huff Dunlap. *Why Johnny Can't Concentrate: Coping with Attention Deficit Problems.* Bantam Books, 1990. Parents will appreciate the author's specific directions for applying positive discipline at home.

Opportunities for the Learning Disabled. 113 Garfield Street, Oak Park, IL 60304. Time Out to Enjoy, Inc.

Osman, Betty B. *Learning Disabilities, A Family Affair.* New York, NY: Random House, 1979. A gold mine of practical advice on how to cope.

Osman, Betty. *No One to Play With: The Social Side of Learning Disabilities.* New York, NY: Random House, 1982.

Ross, D.M. *Hyperactivity.* New York, NY: John Wiley and Sons, 1976.

Silver, Larry. *The Misunderstood Child.* New York, NY: McGraw Hill, 1984. Revised 1988. A guide for parents of children with learning disabilities.

Smith, Sally L. *No Easy Answers: The L.D. Child at Home and School.* (2nd ed.) Bantam Publisher, 1980-81.

Stevens, S. *The Learning Disabled Child: Ways That Parents Can Help.* Winston Salem, NC: John F. Blair, 1980.

Swenson, Sally Shearer; Weisberg, Phyllis Gilman. *Questions and Answers about Learning Disabilities: The Learning Disabled, Their Parents and Professionals Speak Out.* Austin: Pro-Ed, 1988. Interviews regarding the impact of learning disabilities on emotional life - how families cope, manage, survive.

Vitale, Barbara Meister. *Unicorns Are Real.* Rolling Hills Estates, CA: Jalmar Press, 1982. Deals with learning disabilities.

Weiss, Elizabeth. *Mothers Talk About Learning Disabilities.* Prentice-Hall, 1990. Excellent book to aid understanding of the often-confusing designation of learning disabled. Wealth of good advice on how to be an informed and effective advocate for a child with learning disabilities at home and at school.

Weiss, Helen and Weiss, Martin. *Survival Manual: Case Studies and Suggestions for the Learning Disabled Teenager.* Treehouse Associates, 1974.

Wender, Paul. *The Hyperactive Child, Adolescent and Adult: Attention Deficit Disorder Through the Life Span.* New York, NY: Oxford University Press, 1987.

Wender, Paul. *The Hyperactive Child and the Learning Disabled Child: A Handbook for Parents.* Crown, 1978. An enlarged and updated version of Dr. Wender's 1973 book, *The Hyperactive Child.* This edition brings new information concerning drug treatment of hyperactivity and the management of children with hyperactivity and learning disabilities.

Films

Mark. (10 min., color, 1978) Available from University Film and Video, University of Minnesota, Suite 108, 1313-5th Street SE, Minneapolis, MN 55414, (612) 627-4270. Produced by Encyclopedia Britannica: W.G.B.H. TV. Teenager Mark has a reading disability and tells of determination to cope with the problem with the help of his father who also has a learning disability.

Organizations

National organizations include:

ACTION for Brain Injured Children
Osceola, WI 54020
Monthly information bulletin, directory and treatment service.

Council for Exceptional Children (CEC), and its Division for Children with Learning Disabilities (DCLD)
1920 Association Drive
Reston, VA 22091
(703) 620-3660

Learning Disabilities Association of America
(see Disability List)
4156 Library Road
Pittsburgh, PA 15234
(412) 341-1515, 341-8077

Orton Society
8415 Bellona Lane
Towson, MD 21204
(301) 296-0232

Organizations for siblings:

Siblings Understanding Needs (SUN)
Department of Pediatrics C-19
University of Texas Medical Branch
Galveston, TX 77550 (newspapers by siblings)

Sibling Information Network
Department of Education Psychology
Box U-64
The University of Connecticut
Storrs, CT 06268 (newspaper for siblings)

State organizations and agencies are listed in Additional Resources Section at the end of the manual.

Multiple-disabilities

What is multiply-disabled?

The Federal law, P.L. 94-142, defines another category of disability — **multi-disabled**. Multi-disabled refers to children with more than one serious disability (e.g., mental retardation and blindness, or orthopedic disabilities and deafness, etc.), the combination of which causes such severe educational problems that they cannot be accommodated in special education programs solely for one of the impairments. These children present very special needs for their families and educators, and are often in special classrooms.

Other terms often used by school systems and educators to describe this population of students may include "severely disabled," "multiply disabled," and "severely and profoundly disabled."

Resources

Burkig, Thomas O.; Edwards, Sherry Ann. *On The Inside — Looking Out.* Special Education Press, 1979. Sherry Ann Edwards is nonverbal and has physical disabilities with congenital spastic quadriplegia. She and her co-author, a psychologist, were able to set up a unique communication system and as a result this remarkable book was written; it describes life in institutions, and its affect on the persons who live and work in them.

Kelley, Mary Jane, ed. *Yes They Can! A Primer For Educating The Severely and Profoundly Retarded.* Bethesda Lutheran Home, 1978. Systematic steps for teaching children and adults with severe retardation practical skills such as independent grooming and response to simple commands.

McInnes, J.M.; Treffry, J.A. *Deaf-Blind Infants and Children.* University of Toronto Press, 1982. Much available information from various professionals and centers working with children who are deaf-blind is assembled in this guide which includes methods and activities to encourage development in the areas of social and emotional skills, communication, gross and fine motor ability, perceptual and cognitive-conceptual understandings, orientation and mobility, and life skills.

Thomas, M. Angele, ed. *Developing Skills in Severely and Profoundly Handicapped Children.* Council for Exceptional Children, 1977. Pick up some teaching techniques in this collection of essays, in particular from the articles on teaching eating skills and other practical self-help tasks.

Organizations

National organization:

TASH:
The Association for the Severely Handicapped
7010 Roosevelt Way NE
Seattle, WA 98115
(206) 523-8446

State organization:

MNASH
Minnesota Association for the Severely Handicapped
Suite 494 North
1821 University Avenue
St. Paul, MN 55104
(612) 646-6136

Emotional Disorders

What is an emotional disorder?

P.L. 94-142 includes the phrase "seriously emotionally disturbed" to describe children who should be served under its provisions. These children, according to federal criteria, must exhibit one or more of the following characteristics over a long period of time and to a marked degree, which adversely affect their educational performance:

a. an inability to learn which cannot be explained by intellectual, sensory, or health factors
b. an inability to build or maintain satisfactory interpersonal relationships with peers and teachers
c. inappropriate types of behavior or feelings under normal circumstances
d. a general pervasive mood of unhappiness or depression
e. a tendency to develop physical symptoms or fears in association with personal or school problems

Current estimates from the National Institute for Mental Health suggest that 12% of all children are in need of mental health services. Approximately 1.5% of all children have an emotional disorder severe enough to require special education services.

A meeting of education and mental health experts, convened in 1986, led to the formation of a national coalition of the two disciplines to develop a plan of action to better serve children with serious emotional disorders. Because such children frequently receive multi-agency service, the National Mental Health and Special Education Coalition has focused on developing recommendations for collaborative and coordinated social, emotional, behavioral, and educational services.

The 1989-90 Minnesota Child Count indicated 10,008 school-aged children with emotional or behavioral disorders were receiving special education services.

Resources

Books for adults

A Guidebook for Parents of Children with Emotional Disorders. PACER Center, Inc. (Parent Advocacy Coalition for Educational Rights), 4826 Chicago Avenue South, Minneapolis, MN 55417-1055, (612) 827-2966. Revised in 1991, it focuses on resources in the state of Minnesota, but also provides information of general relevance in any state, 1991.

Apter, Steven J.; Conoley, Jane Close. *Childhood Behavior Disorders and Emotional Disturbances*. Englewood Cliffs, NJ: Prentice-Hall, 1984.

Cantor, Sheila. *The Schizophrenic Child: A Primer for Parents and Professionals*. The Eden Press, distributed by University of Toronto Press, 1982.

Craig, Eleanor. *If We Could Hear the Grass Grow*. New York, Simon and Schuster, 1983. A dedicated teacher, twelve troubled children and the summer that changed all their lives.

Des Jardins, Charlotte. *How to Get Services By Being Assertive*. Coordinating Council for Handicapped Children, Chicago, IL 1985.

Des Jardins, Charlotte. *How to Organize an Effective Parent Advocacy Group and Move Bureaucracies*. Coordinating Council for Handicapped Children. Chicago, IL 1985.

Dobson, J. *The Strong-willed Child*. Wheaton, IL: Tyndale, 1983. Discipline techniques for the assertive/aggressive child.

Early, Theresa J. *What You Need to Know About Your Child with an Emotional Disability and the Individualized Educational Plan (IEP)*.

The University of Kansas School of Social Welfare, Twente Hall, Lawrence, KS 66045-2510, August, 1989.

Eberlein, Dianne. *The Handbook for Drugs of Children with Special Needs*. Drugwise Communications, 513-2nd Avenue SE, Minneapolis, MN 55414, 1988. Comprehensive chapters on medication and hyperactivity, epilepsy and anti-convulsants, emotional disorders and antipsychotic medications.

Knitzer, Jane; Steinberg, Zina. *At the Schoolhouse Door*. Bank Street College of Education, 1990. An examination of progress and policies for children with behavioral and emotional problems.

Lashter, Miriam et al. *Mainstreaming Preschoolers: Children with Emotional Disturbance*. DHEW Publication #78-3115. U.S. Government Printing Office, Washington, DC 20402. A guide for teachers, parents and others who work with preschoolers who have emotional disorders.

McCoy, Kathleen. *Coping with Teenage Depression: A Parent's Guide*. New York, NY: New American Library, 1982.

McElroy, Evelyn. *Children and Adolescents with Mental Illness, A Parent's Guide*. Woodbine House, 1989. Information from doctors, nurses, educators and parents about dealing with the systems that serve children with emotional disturbance.

Mental Health Association in Hennepin County. *Your Child's and Adolescent's Mental Health, A Resource Guide for Parents*. Minneapolis, MN: Mental Health Association, 1988.

Oliver, Betty. *The ABC's of Hanging On While Raising a Family with a Disturbed Child*. Claitor's Publishing Division, 3165 South Acadian, PO Box 3333, Baton Rouge, LA 70821, 1976. A book with useful suggestions written by the parent of a young child who is emotionally disturbed.

Pappanikou, H.J.; Paul, James L., eds. *Mainstreaming Emotionally Disturbed Children*. Syracuse University Press, 1977. Thoughtful arguments concern the problems and benefits of mainstreaming a child who is emotionally disturbed into the regular classroom.

Reaves, John and Austin, James B. *How to Find Help for a Troubled Kid*. Henry Holt, 1990. A thorough guide to getting help for adolescents who need it, whether their problem is depression, addiction or delinquency. Strategies recommended.

Rothenberg, Mira. *Children with Emerald Eyes*. Dial, 1977. This is a tender and beautiful account of case histories involving the treatment of children who are severely disturbed. The author is the co-founder and clinical director of the Blueberry Treatment Center.

Taking Charge: A Handbook for Parents Whose Children Have Emotional Handicaps. Families as Allies Project, Research and Training Center to Improve Services for Seriously Emotionally Handicapped Children and Their Families. Portland State University, Portland, OR 97207-0751, 2nd ed., August, 1988.

Torrey, E. Fuller. *Surviving Schizophrenia - A Family Manual*. New York: Harper & Row, 1983.

Turecki, S.; Tonner, L. *The Difficult Child*. New York, NY: Bantam, 1985. A how-to book for understanding and managing the hard-to-raise child.

Turnbull, Ann P. and Turnbull, H. *Parents Speak Out: Views from the Other Side of the 2-Way Mirror*. Columbus, OH: Chas. E. Merrill, 1978.

Films

For teachers: *He Comes from Another Room*. (28 min., color, National Institute of Mental Health, 1974). An excellent documentary in which teachers confront the problems of integrating children who are emotionally and physically disabled into the mainstream of public education. Available from National Audio Visual Center, GSA, Reference Section SG, Washington, DC 20409.

Let's Be Friends. (7 min., color, sound, 1977). Available from University Film and Video, University of Minnesota, 1313-5th Street SE, Suite 108, Minneapolis, MN 55414, (612) 627-4270. Produced by Encyclopedia Britannica. A child who is emotionally disturbed reacts rudely when the teacher leaves the room in charge of another student. The children remember the teacher's advice. (P, M, U)

Videotapes

Parent's Voices: A Few Speak for Many. Produced by PACER for the Families as Allies Project at Portland State University, 1987. Three parents speak about the problems encountered in seeking appropriate mental health services for their child (Trainer's Guide accompanies). A new video will be available in early 1991.

Why Won't My Child Pay Attention? 1989. Neurology, Learning and Behavior Center, Salt Lake City, UT. Dr. Sam Goldstein, a child psychologist, helps parents and teachers who have hyperactive or inattentive children to recognize symptoms and understand a child's behavior problems in order to deal effectively with them.

National Organizations

PARENT ORGANIZATIONS

The Federation of Families for Children's Mental Health (a parent run organization)
1021 Prince Street
Alexandria, VA 22314-2971
(703)684-7710

National Alliance for the Mentally Ill
P.O. Box NAMI
Arlington, VA 22216
Toll-free 1-800-950-NAMI

PROFESSIONAL ORGANIZATIONS

Child and Adolescent Service System Program (CASSP)
National Institute of Mental Health
Parklawn Building, Room 7C-14
5600 Fishers Lane
Rockville, MD 20857
(301) 443-1333

Children's Defense Fund
122 C Street NW, Suite 400
Washington, DC 20001

Council for Children with Behavior Disorders (CCBD)
(A Division of Council for Exceptional Children)
1920 Association Drive
Reston, VA 22091
(703) 620-3660

National Mental Health Association
1021 Prince Street
Alexandria, VA 22314-2971
(703) 684-7722

Autism

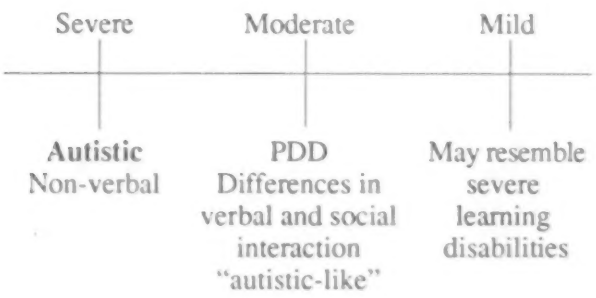
What is autism?

Autism is a brain disorder that severely impairs the way sensory input is assimilated causing problems in communication, social behavior, and irregularity in learning. The essential features typically appear prior to three years of age and include several factors.

There are disturbances of developmental rates and sequences. Normal coordination of motor, social-adaptive, and cognitive skills is disrupted. Delays, arrests, and/or regressions occur among or within each of these areas. There are children who range from quite severely impaired to very verbal and high functioning but who still exhibit numerous behaviors associated with autism.

There are disturbances of responses to sensory stimuli, usually over-reaction or under-reaction. Typical behaviors may include such things as close visual scrutiny, unusual responses to sound, touch, and smell, whirling about without dizziness, and unusual posturing. Children who are not as severely affected may be labeled with PDD or Pervasive Developmental Disorder. There seems to be a spectrum or continuum of autism. If it were drawn out, it might possible look like this:

Spectrum of autistic behavior



Questions most often asked of a child with autism

Is s/he deaf?

No, but s/he has very limited speaking skills.

What happened to her/him? Or, why is s/he like that?

No one really knows why, but evidently, it seems that her/his brain works **differently** than yours or mine.

What disease does s/he have? Or, is s/he sick?

Autism is not a disease. You can't catch it!

What is autism?

Difficulty in understanding what you see or hear.

Will s/he learn to talk?

No one knows for sure, but s/he's learning new words by being with people who talk to her/him and care about her/him!

Often speech, language awareness, and nonverbal communication are affected in a child with autism The child may find it difficult to relate appropriately to people, events, and objects, preferring self-stimulating behaviors such as finger flexing and slapping the face, etc. Autism is estimated to affect four or five children out of every 10,000 births and is four times more common in boys than girls. It has been found throughout the world in families of all racial, ethnic, and social backgrounds. Most scientists now agree that the causes of autism are **biological, not psychological.**

Common manifestations of autism *

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Resources

Bachrach, Ann W.; Mosley, Ada R.; Swindle, Faye L.; Wood, Mary M. *Developmental Therapy for Young Children with Autistic Characteristics.* University Park Press, 1978. Curriculum for teaching and working with children who have autism. Explicit directions for parents to help their preschoolers; educational strategies described.

Balow, B.; Reid, G. *Autism Sourcebook for Parents and Professionals.* University of Minnesota, 1978.

Christopher, Barbara; Christopher, William. *Mixed Blessings.* Father Mulcahy of TV's MASH and wife tell, with dignity and realism, their experiences of raising their son, Ned, who is autistic.

Cohan, Donald J.; Donnellan, Anne M., eds. *Handbook of Autism and Pervasive Developmental Disorder.* 1987. Provides an overview of autism from perspectives of psychology, biology, neurology, physiology and pharmacology.

Delacato, Carl H. *The Ultimate Stranger: The Autistic Child.* Delacato discusses his sensory approach to autism as a neurogenic disorder.

Donnellan, Anne, ed. *Classic Readings in Autism.* New York, NY: Teachers College, 1985. With the help of a panel of international experts, Anne Donnellan has selected 21 samples of "noteworthy medical, educational, psychological, and linguistic papers," beginning with Leo Kanner's first description of 11 children with autism.

Donnellan, Anne; LaVigna, Gary W. *Progress Without Punishment: Effective Approaches for Learners with Behavior Problems.* 1988. Advocates explore the use of alternative, non-aversive intervention procedures.

Donnellan-Walsh, A.; Gossage, L.D.; LaVigna G.W.; Schuler, A.; Traphagan, J.D. *Teaching Makes a Difference: A Guide for Developing Successful Classes for Autistic and Other Severely Handicapped Children.* Santa Barbara County Schools, 1976.

Hart, Charles. *Without Reason - A Family Copes with Two Generations of Autism.* 1989. A sensitive account revealing a family's struggle and ways of coping.

Kaplan-Fitzgerald, Karen. *Reach Me, Teach Me: A Public School Program for the Autistic Child. A Handbook for Teachers and Administrators.* Academic Therapy Pub., 1977. Comprehensive program for teaching children with autism in a public school, giving explicit guidelines for classroom environment, qualifications of the teacher, support services, and parent participation. Curriculum objectives and activities to achieve them, parent contribution to the school program and home-based educational activities are listed.

Kozloff, Martin A. *Reaching the Autistic Child: A Parent Training Program.* Cambridge, MA: Brookline Books, 1983. The author reviews theories and therapies and presents in detail a parent training program employing behavior modification.

Long, Nicholas, ed. *Conflict in the Classroom: The Education of Children with Problems.* Belmont, CA: Wadsworth Publishing Co., Inc., 1976. A collection of essays focusing on educational approaches that work.

Lovaas, Ivar. *The Autistic Child: Language Development Through Behavior Modification.* New York, NY: Irvington Publishers, 1976.

McGee. *Gentle Teaching.* 1987. Provides instruction in dealing with severely behaviorally challenging persons using humane presence and interaction as the primary motivation for change.

Paluszny, Maria J. *Autism: A Practical Guide for Parents and Professionals.* New York, NY: Syracuse University Press, 1979.

Powers, Michael, ed. *Children with Autism, A Parent's Guide.* Index, reading list, glossary and resource guide.

Richs, D.M.; Wing, L. "Language, Communication, and the Use of Symbols in Normal and Autistic Children". *Journal of Autism and Childhood Schizophrenia.* 1975.

Rimland, Bernard. *Infantile Autism: The Syndrome and its Implications for a Neural Theory of Behavior.* New York, NY: Appleton-Century-Crofts, 1974.

Ritvo, Edward, ed. *Autism: Diagnosis, Current Research and Management.* New York, NY: Spectrum Publications, Inc., 1976.

Rutter, Michael; Schopler, Eric. *Autism: A Reappraisal of Concepts and Treatment.* New York, NY: Plenum Publishing Corporation, 1976.

Simons, Jeanne; Oishi, Sabine. *The Hidden Child.* The Lenwood Method for Reading the Autistic Child.

Simons, Robin. *After the Tears.* 1987. Parents talk about rearing a child with a disability.

Smith, Marcia Datlow. *Autism and Life in the Community.* Baltimore, MD: Brookes Publishing Co., 1989. Successful intervention for behavioral challenges.

Swift, Marshall S.; Spical, George. *Alternative Teaching Strategies.* Champaign, IL: Research Press, 1975, Based on a long series of research projects, this book offers teachers a vast storehouse of workable ideas and techniques to reach children with extreme learning difficulties to help them improve their capacity to learn.

Wing, Lorna. *Autistic Children: A Guide for Parents and Professionals.* (2nd ed.) New York, NY: Brunner/Mazel, 1985. This is a clear, sympathetic guide, by a world-renowned authority, to the condition of autism in children.

Wing, Lorna. *Children Apart.* New York, NY: Lyle, Stuart, 1978.

Michigan Society for Autistic Citizens (MSAC) has a bookstore which stocks and sells books dealing with autism and general disability information. Write or call for information:

MSAC Bookstore
530 West Ionia Street, Suite C
Lansing, MI 48933
(517) 487-9260

Films

The Twin Cities Society for Children and Adults with Autism, Inc. has created two training films about autism.

Introduction to Autism: Overview, 1986.

Introduction to Autism: Communication, 1986.

These two films, which were designed for use by service providers, are now marketed throughout the United States.

Organizations

National organizations include:

Autism Society of America, Inc. (formerly NSAC, National Society for Autistic Children)
8601 Georgia Avenue, Suite 503
Silver Spring, MD 20910
(301) 565-0433
FAX: (301) 565-0834

State organizations and agencies are listed in Additional Resources Section at the end of the manual.

The material on autism was contributed by Joan Schoepke and updated by Jeanette Behr; both are parents of children who have autism.

Other Health Impairments

For children who have medical problems that have a bearing on their academic and extra-curricular participation, a special category called "other health impairments" exists.

P.L. 94-142 defines **other health impaired** as having "limited strength, vitality or alertness, due to chronic or acute health problems such as heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, or diabetes, which adversely affects a child's educational performance." In Minnesota, 507 children with health impairments were receiving special education services during the 1989-90 school year.

These children are entitled to all the laws and rights and special education considerations covered under the term "handicapped child".

Following are some of the health impairments:

Cystic Fibrosis

An inherited condition in which the mucous glands (including those in the lungs) secrete thick sticky mucous, cystic fibrosis results in digestive and breathing problems that severely affect a child's health.

The mucous produced by cystic fibrosis affects the production of digestive enzymes which break down food in the digestion process. Children take medication to help control these problems.

In the lungs, the sticky mucous interferes with the intake transfer of oxygen from the air to the blood, and the exhalation transfer of carbon dioxide. Children receive postural drainage therapy (a routine pounding on the chest in such a way as to loosen the mucous) and aerosol therapy. The frequency of these routines depends on the condition of the child.

New research has found that persons who have from cystic fibrosis lack working copies of the cystic fibrosis gene. This defect leads to the deadly respiratory disease. By inserting healthy genes, the disease symptoms may be reversed.

Films

Films with an * are available from University Film and Video, University of Minnesota, Suite 108, 1313 - 5th Street SE, Minneapolis, MN 55414; (612) 627-4270.

John. * (10 min., color, 1978). People You'd Like to Know Series: produced by W.G.B.H. TV, Encyclopedia Britannica. John helps friends come to understand his cystic fibrosis with his constant coughing and need for medication. (M, U)

It's Up To Me. * (7 min., color, 1977). I Can, I Will Series: produced by Alan P. Sloan - Avatar Learning, Inc., Encyclopedia Britannica. Friends learn that Scott needs to have medication available at all times and why he needs to avoid Jill's kitten because of asthma.

Juvenile Diabetes

What is diabetes?

Diabetes is a disease of the pancreas which prevents the body from turning carbohydrates (sugars and starches) into energy. In a person who does not have diabetes, carbohydrates, present in many types of food, are digested and turned into glucose. Then insulin, a hormone secreted by the pancreas, acts on the glucose, so that the body may use it for energy or store it for later use. In a person with diabetes, the body either cannot produce enough insulin or it cannot properly use the insulin it produces. As a result, excess glucose accumulates

in the blood instead of being converted into energy. The glucose then passes through kidneys into the urine. The body must then breakdown fat for energy which causes an excess of fatty acids, a byproduct of metabolized fat. The excess fatty acids poison the body leading to a condition called acidosis. If untreated, this condition causes diabetic coma and death.

Two types of diabetes

Type I: Insulin-Dependent or Juvenile Diabetes - This is the more severe form of diabetes. It affects 500,000 children and adolescents in the United States. It appears abruptly during childhood or adolescence and develops very rapidly with acute symptoms. It requires immediate medical attention.

Type II: Non-insulin Dependent, or Maturity-Onset Diabetes - This occurs most often in overweight adults over 35 years of age. The onset is slower, the symptoms less acute. In non-insulin dependent diabetes, the pancreas does produce insulin, but the insulin is not able to work fully. Glucose builds up in the blood and gradually damages many parts of the body. This type of diabetes is treated by diet, exercise and, if necessary, medication to stimulate insulin production. An estimated 10 million Americans suffer from this form of diabetes.

Causes

Heredity appears to be a factor in the development of juvenile diabetes. A child is more likely to have diabetes if one or both of his parents have the disease. However, most experts agree that other, unknown factors may be contributing causes of diabetes.

Symptoms

The onset of juvenile diabetes can occur anytime in childhood or adolescence. The symptoms are very acute. They consist of frequent urination, unusual thirst, rapid weight loss, fatigue, weakness, irritability, nausea, vomiting, and extreme hunger. These symptoms occur very suddenly and demand immediate medical attention.

Treatment

There is no cure for diabetes. Insulin can control the disease, but it does not cure diabetes.

Diabetes is a life-long, chronic disease which requires continual management. Before the discovery of insulin in 1921, most children with diabetes lived no more that 2 years after the onset of the disease. Insulin has dramatically improved the future for children with diabetes. However, it is important to remember that insulin only helps control diabetes. It does not cure it. Very careful diabetes management is individually planned by the child's physician. It includes a diet plan, exercise and insulin.

Diabetic control involves maintaining the proper balance between insulin and food sugar allowing the blood sugar level to stay within normal limits. A proper diet is essential to maintain this balance. A child with diabetes needs a well-rounded diet that is free of concentrated sweets such as candy, soda pop and frosting. Concentrated sweets release sugar more rapidly than can be balanced by insulin. It is necessary that the child eat adequate meals on a regular schedule with snacks in between.

Exercise is very important to the child with diabetes. There is a very strong correlation between overweight and diabetes in adults, indicating that obesity interferes with insulin productivity. Routine exercise helps insulin work, and it helps keep weight down. Children with diabetes can and should do all of the physical activities that other children do.

Generally, persons who develop diabetes later in life (Maturity-Onset Diabetes) are able to control their diabetes with diet plus medication to stimulate the pancreas to produce more insulin. They do no require insulin injections. However, children with juvenile diabetes almost always require insulin injections to live. They have no pancreatic function. Insulin is not a medication. It is a body hormone secreted by the pancreas. The insulin used in diabetic treatment is taken from the pancreas of animals and injected into the child. Injections are given one or several times a day. By the time a child is 9 or 10, s/he has usually learned to give her/his own injections. The injections are usually given in the arms, thighs, and/or abdomen. The site is varied from day to day.

Balance is the key word in the treatment of diabetes. As long as diet, exercise and insulin are in balance, the child functions normally. When an imbalance occurs, serious problems result.

Imbalance

Insulin Reaction (Hypoglycemia) - This occurs when the blood sugar level is too low. This is caused by too much insulin, too little food, and/or sweating. Symptoms are dizziness, hunger, blurred vision and pale skin. The onset is sudden. The treatment is some form of sugar ingested immediately such as fruit juice, regular pop (not diet) or two pieces of hard candy. It is essential that a child with diabetes either carry with him/her or have access to some form of carbohydrate in the event of an insulin reaction. Generally, the child will feel better within a few minutes of eating some form of sugar, but occasionally s/he may need to rest for 20 minutes or so before resuming normal activity. Most insulin reactions can be prevented by taking the right amount of insulin, eating adequate meals at regular times, remembering between meal snacks, and by eating additional carbohydrates before excessive exercise.

Acidosis (Hyperglycemia) - This is the opposite of an insulin reaction. It occurs when the insulin level is too low because of neglected injections, poor diet or infections. This is a serious condition that can lead to diabetic coma. The symptoms which come on gradually are flushed, dry skin, thirst, nausea, vomiting, abdominal pain, and/or a fruity odor to the breath. Treatment is to call a physician who would administer the proper amount of insulin. The prevention of acidosis is to take prescribed amounts of insulin, follow the prescribed meal plan and increase insulin at the time of injection.

Since the balance of insulin and sugar is so critical to proper management of diabetes, tests have been devised to monitor this balance. The best way to check on blood sugar can be done by blood tests. Devices are now available for home use to aid persons with diabetes in testing their own blood and evaluating their blood sugar level. The methods used are either comparing the color of a drop of blood with a color chart or using a special meter which evaluates and gives a read-out on the glucose level. Usually, the test is done four times each day before meals and at bedtime. The check can be done by ages 9 or 10, or younger.

Another way to check the blood is to check the amount of sugar in the urine. When blood sugar is high, the sugar in the urine is also high. Usually the test is done before mealtime, and at bedtime. However, it is not as accurate as blood testing. Most doctors recommend blood testing.

Diabetes is a serious disease. It can lead to serious eye, nerve, and kidney damage. However, most experts agree that careful control of blood sugar levels can prevent or reduce the severity of these complications.

Puppet used to portray a child with diabetes

The puppet who has diabetes is Eric. He feels faint and shaky and has an insulin reaction. After drinking some fruit juice and eating some food, he feels better. Carmen and Mitch ask lots of questions.

Questions Eric has been asked about his diabetes

How can you not eat any candy, cake or ice cream?

> I can balance desserts into my meal plan on occasion. I can eat angel food cake, plain yellow cake and ice cream. I substitute it for a bread or carbohydrate serving and a fat serving. I can eat dessert two times a week. A person with diabetes eats a nutritious diet that everyone should be eating. No one needs to eat all those gooey, rich desserts, anyway. Other desserts that I can substitute are: pudding - 1/2 cup; plain donut - 1; cookies - 3; Dairy Queen ice cream cone, vanilla - 1 small cone.

Do you have to take shots everyday? How can you stand it?

> I give myself shots everyday, usually three or four times a day in different areas of my

body (thigh, arm, or my stomach). It doesn't really hurt. It kinda feels like a pinch. You get used to it.

Eric, don't you hate eating certain foods and taking medicine everyday?

It's my routine to stay healthy. Most people dislike the strict schedule. But, I'm learning to fit it into my life. As I understand my diabetes, I seem to work it out pretty well. Also, I feel better when I follow my plan and my routine.

What are the myths about diabetes?

People think that I need to buy special food, cannot do normal activity and never eat any desserts. But, now you know that's not true.

Resources

The following list of resources was provided by the American Diabetes Association, Minnesota Affiliate, Inc.

Anderson, James W. *Diabetes, A Practical New Guide to Healthy Living*. Areo Publishing Inc. 1981.

Belmonte, Mini M. *The Diabetic Child and Young Adult*. Montreal-London. Eden Press, Inc. 1983.

Born, Dorothy. *Diabetes In the Family*. New York, NY: American Diabetes Association. 1982.

Brothers, Milton J. *Diabetes The New Approach*. New York, NY: Gosset and Dunlap. 1976.

Cull, John G.; Hardy, Richard E. *Counseling and Rehabilitating the Diabetic*. Springfield, IL: Charles C. Thomas Co.

Danowski, T.S. *Diabetes As a Way of Life*. New York, NY: Coward-McMann and Geogrefan, Inc.

Dierman, June; Toohey, Barbara. *The Diabetic Question and Answer Book*. Los Angeles, CA: Sherbourne Press. 1977.

Dierman, June; Toohey, Barbara. *The Diabetes Total Health Book*. Los Angeles, CA: J.P. Tarcher, Inc. 1981.

Franz, Marion J. *Exchanges For All Occasions*. Minneapolis, MN: International Diabetes Center. 1983.

Graber, Alan L.; Christman, Barbara G.; Rawlings, Virginia B.; Boehm, Frank H. *Diabetes and Pregnancy*. Nashville, TN: Vanderbilt University Press.

Haig, B.; Moynihan, P. *Whole Parent, Whole Child: A Parent's Guide to Raising the Child with a Chronic Heart Condition*. Minneapolis, MN: Diabetes Center. 1988. How to help the child with a chronic health problem lead the fullest life possible. This book is written for families and health professionals who care for children with many different conditions.

Kipnis, Lynn Adler. *Susan, You Can't Catch Diabetes From a Friend*. Gainesville, FL: Triad Publishing Co. 1979.

Minnesota Department of Health Services for Children with Handicaps (SCH), *Guidelines of Care for Children with Special Health Care Needs - DIABETES*. (Booklet) 1990. Call toll-free 1-800-728-5420 (Voice or TDD).

Mirskey, Stanley; Heilman, Joan Rattner. *Diabetes: Controlling It the Easy Way*. New York, NY: Random House, Inc. 1981.

Pray, Lawrence M. *Journey of a Diabetic*. New York, NY: Simon and Schuster. 1983.

Rifkin, Harold; Raskin, Philip. *Diabetes Mellitus*. New York, NY: American Diabetes Association. 1981.

Sims, Dorothea F. *Diabetes, Reach For Health And Freedom*. C.V. Mosby Co. 1980.

The material was reviewed and updated by Ceci Shapland, R.N., M.S.N., diabetes consultant, parent of a child with disabilities, and regional technical assistance coordinator of CAPP (Collaboration Among Parents and Professionals) at PACER Center.

Organizations

American Diabetes Association (ADA)
Diabetes Information Service Center
1660 Duke Street
Alexandria, VA 22314
1-800-ADA-DISC
(catalog of information available)

Juvenile Diabetes Foundation International (JDF)
432 Park Avenue South
New York, NY 10016
1-800-223-1138
(Diabetes research - pamphlets available)

National Diabetes Information Clearinghouse (NDIC)
Box NDIC, 9000 Rockville Pike
Bethesda, MD 20892
(301) 468-2162

Epilepsy

What is epilepsy?

Epilepsy is a chronic disability that can affect persons of all ages. It is not a disease, but rather a disorder of the brain characterized by temporary but recurring seizures in which there are uncontrolled electrical discharges from the brain cells. During the brief time of these electrical discharges, the person's consciousness, behavior, bodily functions, sensations, and motor activity can be altered.

The Epilepsy Foundation of America notes that the "epilepsy is a medical condition that is varied and complex; hence all persons with it are not affected similarly. The impact on individuals runs the gamut from those who are able to live normal or near-normal lives, to those who are severely impaired by epilepsy and its consequences." It is estimated that at least two million Americans have active epilepsy, and that about 100,000 new cases develop each year, three-fourths of these in children and adolescents.

Types of seizures

Seizures differ in frequency and in the type of exhibited behavior. The three most common types of seizures are:

Absence (petit mal) - a very brief (3-30 second) lapse of consciousness with a blank stare, rapid eye blinking, or eyes rolling upward. The child does not hear or see anything during this lapse. This seizure is frequently not detected because it is over so rapidly and the child resumes activity immediately.

Generalized tonic-clonic (grand mal) - is more alarming to the observer because of the sudden loss of control. The child loses consciousness and falls to the ground. The body stiffens (tonic phase) and then begins a rhythmic jerking of all parts of the body (clonic phase). Breathing is labored or may appear to stop, which may cause the child to turn blue. Loss of control of the bladder may also occur. The seizure can last from 1-3 minutes and may be followed by confusion, muscle fatigue, and headache. Only if the child passes from one seizure into another without regaining consciousness or if the seizure lasts more than 10 minutes should medical help be sought.

Complex partial (psycho-motor) - Seizures may last from two to four minutes. Behavior during the seizures varies from person to person, but for any one individual the same behavior regularly occurs. Some common behaviors include staring, poorly coordinated automatic behaviors (such as walking aimlessly around the room), fidgeting with clothes, incoherent or irrelevant speech, and lip smacking.

In most instances the cause of epilepsy is unknown. Since it is not a disease, it is not contagious. Some known causes of a seizure disorder are head injuries, fever, convulsions, and diseases of the brain such as meningitis or encephalitis.

The majority of children with epilepsy will have good control of their seizures through daily use of one of the many antiepileptic medications available, and will have only the normal problems of childhood. Some

children with epilepsy will have difficulty in school, and P.L. 94-142 entitles them to the aid they need. An IEP is appropriate for these children.

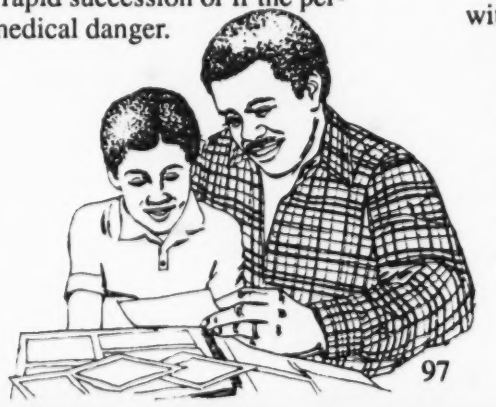
Safety care

Most seizures can be controlled with medication, which is prescribed by a doctor for a particular person. Different kinds of medication help different kinds of epilepsy. Children and adults can participate in many kinds of sports or activities. Exercise, playing sports, or having fun will not make a person have more seizures.

However, if some types of seizures do occur, important help can be provided by friends, teachers, or bystanders. With an absence seizure (petit mal) persons may stare, blink or have mild facial twitching which lasts from 3-30 seconds. A buddy could be assigned to provide missed information, so the person can keep up with the rest of the group.

For persons experiencing a generalized tonic-clonic (grand mal) seizure -

1. Clear things out of the way, so the person won't be hurt by banging against or falling on something sharp or hazardous.
2. Place a folded jacket, blanket, or cushion under the person's head for comfort.
3. Don't place anything hard in the mouth—teeth or jaw may be injured. (The tongue **cannot** be swallowed—it's attached.)
4. Stay by the person until the seizure is over, talking softly and calmly.
5. Call a doctor if there is more than one seizure in rapid succession or if the person is in medical danger.



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For someone experiencing an absence (petit mal) seizure -

1. Person may be staring, blinking, or experiencing facial tics.
2. A buddy could be assigned to provide missed information.

For someone experiencing a complex partial (psycho-motor) seizures -

1. Guide the person away from anything dangerous, if he or she is aimlessly walking around.
2. Stay with the person until the seizure is over.

Feelings about epilepsy

As the Epilepsy Foundation of America stresses, "Understanding epilepsy includes not only understanding seizures and their treatment, but also the social and psychological consequences that accompany the medical condition. For many persons, the social and psychological consequences and problems associated with epilepsy are more disabling than the seizures themselves."

The child with seizures may have a variety of feelings as evidenced by the statements for *Gripping Tales or Living with Seizures*, (Wisconsin Epilepsy Association, Madison, Wisconsin):

> . . . Just when I think I've got it altogether - another seizure comes. It feels like my body is coming apart.

In the book *Exceptional View of Life* (E.J. McGrath, Jr., Island Heritage Ltd: Honolulu, 1977) a person with epilepsy says:

> When I have a seizure and somebody sees it they get scared and wonder what's up. Once when we went on a field trip, the bus left me off and a friend was taking me home. I had a seizure and had to lay down in the driveway. The lady was real scared. She jumped out of her car. She didn't know what to do. I don't

want them to get worried, but there's no way I can stop them from worrying.

I'm happy that people care when they see me and try to help me. I love everybody that cares for me—my parents, my teachers, my doctor who is trying so hard to get me well. They have special feelings. In other words, they have love for me. People treat me very kindly, with respect. Sometimes when I'm going to have a seizure, I can't just walk over and tell them. It doesn't really bother me so much. I've done it so many times.

Puppet used to portray epilepsy

Carmen has a hidden disability. She has had epilepsy since birth. She is in many of the COUNT ME IN scripts as the inquisitive friend. Carmen's friends, even Mitch, never knew about her seizures. He learns that epilepsy is not catching, and it can be controlled with medication. Carmen has not had a seizure this past year, but she remembers what it is like to have had a seizure. She mentions ways a friend can help her if a seizure should occur and that she can do almost anything.

Questions our puppet has been asked

Can I catch epilepsy?

No, you can't catch epilepsy because it's not a disease.

Does it hurt?

No, epilepsy itself doesn't hurt. But, if I bang against something when I have a seizure, I may get hurt.

Is it scary to have a seizure?

Well, when I'm having a seizure, I don't know it-so I'm not scared. But, many people seem scared when they see it. I wish this wasn't so.

How did you get it?

I don't know how I got it. Mom says I've had epilepsy ever since I was real little. But some people have it as a result of head injuries in car accidents, motorcycle accidents, etc.

Aren't you afraid to go places in case you have a seizure?

I used to be, but I love to go places, so I don't worry about it. The medicine I take now helps, and I have very few seizures.

Can you play sports?

Sure, as long as I take my medication, I can participate in any sport or game that I want to play. In fact, when I'm 16, if I haven't had any seizures for six months (laws vary from six months to two years in the United States), I can even get a driver's license.

Simulation activities

Simulation activities are available as part of the "Epilepsy Is . . ." kit (see Resources-Audiovisual materials). Due to the nature of the activities, it is advised not to use them unless they are part of the total lesson. Children need to understand why a person with seizures exhibits the behaviors that are part of the simulations. They also need to discuss the feelings involved and how to help the person who experiences these feelings.

The information on epilepsy was contributed by Sister Ann Vivia Walton of the Comprehensive Epilepsy Program and updated by Janet Mims, clinician nurse, and a PACER board member representing the Minnesota Epilepsy Group.

Resources

Books for children

(P = Primary, M = Middle, U = Upper grade level recommendations)

Aiello, Barbara; Shulman, Jeffrey. *Trick or Treat or Trouble.* A "Kids on the Block" book. 1989. Set around Halloween, this story features Brian, who has epilepsy. (P, M)

All About Epilepsy - Me and My World. Washington, DC: Epilepsy Foundation of America, 1981. Excellent stories for children about epilepsy. (P, M, U) Booklet.

Girion, Barbara. *A Handful of Stars.* New York, NY: Charles Scribner and Sons. 1981. A novel for young people. Julie, a busy high school sophomore, suddenly has epileptic seizures and must learn to live with her condition as doctors attempt to control it through medication. (M, U)

Gripping Tales or Living With Seizures. Wisconsin Epilepsy Association, 1245 E. Washington, Ave., Madison, WI 53703. A book written by children and for children. Original artwork of the children illustrating their views of living with seizures. (M)

Hermes, Patricia. *What If They Knew?* New York, NY: Harcourt, Brace, Jovanovich, 1980. Jeremy has epilepsy and must adjust to living with her grandparents.

McGrath, E.J. *Exceptional View of Life.* Honolulu, HI: Island Heritage, Ltd., 1977. (M, U)

Me and My World, 1981. Epilepsy Foundation of America.

Moss, Deborah M. *Lee, The Rabbit With Epilepsy.* Kensington, MD: Woodbine House, Inc., 1989. (P)

Silverstein, Alvin; Silverstein, Virginia. *Epilepsy.* Philadelphia, PA: J.B. Lippincott Co., 1975. A good introduction for young people. (U)

Books for adults

Cooper, Irving S. Living with Chronic Neurologic Disease: A Handbook for Patient and Family. New York, NY: W.W. Norton, 1976.

Epilepsy: You and Your Child, A Guide for Parents. Washington, DC: Epilepsy Foundation of America. 1985. An excellent pocket-size resource.

Jan, J.E.; Ziegler, R.G.; Guiseppe, E. *Does Your Child Have Epilepsy?* Baltimore, MD: University Park Press, 1983. What parents should know about epilepsy — the realities. Dispels myths that confuse and can terrify.

Lagos, Jorge C. *Seizures, Epilepsy and Your Child.* New York, NY: Harper and Row. 1974.

Lechtenberg, Richard. *Epilepsy and The Family.* Cambridge, MA: Harvard University Press, 1984. Book for people with epilepsy and for those who provide support. Biological basis for diagnosis and treatment, developmental conflicts, and psychosocial adjustments are just a few of the topics covered.

Lovering, Robert. *Out of the Ordinary: A Digest on Disability.* Phoenix, AZ: ARCS, Inc. 1985.

Patterson, Kathryn. *No Time for Tears.* Chicago, IL: Johnson Publications, 1965. The author, who has epilepsy, discusses challenges in her life.

Reisner, Helen, ed. *Children With Epilepsy, A Parent's Guide.* Kensington, MD: Woodbine House. 1988. Helps parents learn about epilepsy and how to cope with it and surrounding issues. Excellent resource.

Sands, Harry; Minters, Frances C. *The Epilepsy Fact Book.* Philadelphia, PA: F. A. Davis Co., 1977.

Schwartz, Jane. *Epilepsy and Physical Activities.* Minnesota Epilepsy League, Inc. 1981. Guidelines for the individual with epilepsy—

parents, siblings, recreation and physical education personnel.

Silberman, Arlene. "Follow-up: I've Stopped Living a Lie!" *Good Housekeeping.* February, 1976. In simple, straightforward style, the wife of a famed author tells how she formerly used excuses rather than tell people the truth about her own case of epilepsy.

Svoboda, William A. *Learning About Epilepsy.* Baltimore, MD: University Park Press. 1979.

Volle, Frank O.; Heron, Patricia A. *Epilepsy and You.* Springfield, IL: Charles C. Thomas. 1977.

Walton, Ann Vivia. *Teaching the Student With Epilepsy: A Dilemma Or An Opportunity.* Epilepsy Foundation of America, 1982. Paper examines educator's role relating to medical, social and psychological problems.

White, Robin. *Be Not Afraid.* New York, NY: Berkeley Publishing Corp., 1972. Account of family life with a son with epilepsy.

Wright, George N., ed. *Epilepsy Rehabilitation.* Boston, MA: Little Brown and Co., 1975.

The Epilepsy Foundation of America (EFA) has established a computerized library resource center on epilepsy. They will research a specific topic and provide a print-out of relevant materials. Write or phone: National Epilepsy Library and Resource Center, 4351 Garden City Drive, Landover, MD 20785. Phone: (301) 459-3700.

Pamphlets

An E.E.G. is Not An Egg. Epilepsy Education, St. Louis Park, MN. Helps child prepare for first E.E.G. (electroencephalogram).

Antiepileptic Medications: Why? Epilepsy Education, St. Louis Park, MN. This informative presentation offers patients with epilepsy insight into the "seizure threshold."

Because You Are My Friend. Washington, DC: Epilepsy Foundation of America, 1978. In this first-person narrative, a boy confides to his friend that he has epilepsy and proceeds to explain all the ramifications. Also in Spanish. (P, M)

Epilepsy: A Positive I.D. Epilepsy. Epilepsy Education, St. Louis Park, MN. Is designed to help first respondents (police, fire fighters, paramedics) recognize the most common epileptic seizures.

Epilepsy and Sports Participation - Reference #105. Epilepsy Education, St. Louis Park, MN. Can a person with epilepsy be involved in sports?

Epilepsy and the School-Age Child - Reference #104. Epilepsy Education, St. Louis Park, MN. Understanding psychological and social needs of school-age children with epilepsy.

Epilepsy: Medical Aspects - Reference #103. Epilepsy Education. 5775 Wayzata Blvd., Suite 255, St. Louis Park, MN 55416. A medical perspective of epilepsy.

Audiovisual materials

Epilepsy Is. Epilepsy Foundation of America, 1979. (10 - 15 min.) A classroom lesson, available in slide/tape and filmstrip, designed to teach children what happens when a person has a seizure, why it happens, and what they can do to help. Kit includes teacher's guide, simulation activities, and slide/tape or filmstrip. Available for two levels: ages 5-12, and 12 to adult.

Epilepsy, First Aid for Seizures. Epilepsy Foundation of America, 1980. (12 min., 16mm or video cassette).

Epilepsy, the Child and the Family. Epilepsy Foundation of America, 1986. (14 min.) Explains basic issues, impact on the child and family.

Images of Epilepsy. Colorado Epilepsy Association, 1835 Gaylord St., Denver, Colorado 80206. A 16 mm color film that describes the three most common types of seizures as seen through the eyes of students who experience

the seizures. Can be used with students from grades 4 - 12.

Tim Talks About Epilepsy. Pfarrago Information Systems, 4760-22nd Ave. NE, Seattle, WA, 98105. A 16 mm color film. A pantomime presentation coupled with a narrator which describes the nature of epilepsy. For use with students in K-3.

Organizations

Epilepsy Foundation of America
4315 Garden City Drive
Landover, MD 20785
(301) 459-3700
(Pamphlets available, as well as films and videotapes.)

E.F.A. has established a computerized epilepsy resource library system. They will research a specific topic and provide a print-out of all relevant materials. They may be reached at:

National Epilepsy Library and Resource Center
4351 Garden City Drive
Landover, MD 20785
(301) 459-3700
Toll free: 1-800-EFA-1000

State organizations and agencies are listed in Additional Resources Section at the end of the manual.

Additional Resources About All Disabilities

Books for children

Adams, Barbara; Stanfield, James. *Like It Is: Facts and Feelings About Handicaps From Kids Who Know.* Walker & Company. 1979

Biklen, Douglas; Barnes, Ellen. *You Don't Have to Hear to Cook Pancakes: A Workbook on Understanding People.* Syracuse, NY: Human Policy Press, 1977. A delightful book that helps children learn about differences and similarities among people.

Biklen, Douglas; Sakoloft, Michele. *What Do You Do When Your Wheelchair Gets a Flat Tire? Questions and Answers About Disabilities.* Syracuse, NY: Human Policy Press, 1977.

Draus, R. Leo, *The Late Bloomer.* New York, NY: Dutton, 1973. Leo, a tiger, was out of place until he finally bloomed.

Gelfand, Ravina; Patterson, Letha. *They Wouldn't Quit.* Mpls., MN: Lerner Publishing Co., 1962. Stories about adults with disabilities and how they succeeded.

Grealish, Charles A.; Grealish, Mary Jane Von Braunsberg. *The Sneely-Mouthed Snerds and the Wonderoctopus.* Syracuse, NY: Human Policy, 1975. A story about differences.

Griggenheim, Hans. *The World of Wonderful Differences.* New York, NY: Friendly House Publishers, 1960.

Hobby, Janice Hale. *Staying Back.* Gainesville, FL: Triad, 1982. (Ages 7-12) Stories are told from the point of view of seven elementary-school-aged children who are coping with academic failure for a variety of reasons including hearing loss, sickle cell anemia, and a learning disability.

McConnell, Nancy P. *Different and Alike.* Colorado Springs, CO: Current, 1983 (Ages 6-10) This book of facts will help children understand what it's like to have a disability.

McGrath, E. *An Exceptional View of Life.* An Island Heritage, Norfolk Island Australia, 1977. An excellent book of pictures, poems and stories produced by children with disabilities.

Stein, Sara Bonnett. *About Handicaps.* New York, NY: Walker & Co., 1974. Vivid photographs and a simple, honest text unfold the story for the child while parents and teachers can follow an accompanying text that provides more specific detail.

Stein, Sara Bonnett. *A Hospital Story.* New York, NY: Walker & Co.

Taking Charge of Your Life: A Guide to Independence for Teens with Physical Disabilities. Washington, DC: Closer Look—Parents' Campaign for Children and Youth with Disabilities. 1981. Although this 21-page book gives most emphasis to physical disabilities, references are made to all disabilities. Teens without disabilities can gain insight into the lives of their peers with disabilities.

Books for adults

Ackerman, Paul; Kappelman, Murray. *Signals: What Your Child is Really Telling You.* New York, NY: Dial Press/James Wade, 1978.

Aiello, Barbara. *Making It Work: Practical Ideas for Integrating Exceptional Children into Regular Classrooms.* Council for Exceptional Children, Reston, VA, 1975.

Barnes, Ellen; Berrigan, Carol; Biklen, Douglas. *What's The Difference?* Syracuse New York: Human Policy Press, 1978. A valuable resource

for classroom teachers on teaching positive attitudes toward persons with disabilities.

Baskin, Barbara H.; Harris, Karen. *Notes from a Different Drummer.* Available from R.R. Bowker Co., 1180 Ave. of the Americas, New York, NY 10036. A helpful guide to children's literature which summarizes over 300 books portraying persons with disabilities.

Bookbinder, Susan. *Mainstreaming—What Every Child Needs to Know About Disabilities.* Exceptional Parent Press, Room 708, Statler Office Bldg., Boston, MA 02216. Excellent resource book.

Boston Women's Health Book Collective. *Ourselves and Our Children.* New York, NY: Random House, 1978. An interesting book by and for parents which includes insights on parenting children with special needs.

Buscaglia, Leo. *The Disabled and Their Parents: A Counseling Challenge.* Charles B. Slack, 1975. A strong documented appeal to all in helping professions.

Cashdollar, Pat; Martin, Joan. *Kids Come in Special Flavors.* The Kids Come in Special Flavors Co., P.O. Box 652, Dayton, OH 45405, 1978. A kit and book with many ideas for helping children to understand disabilities.

Cleary, Margaret. *Please Know Me As I Am.* Sudbury, MA: Jerry Cleary Co., 1975. This is a book with suggestions for teachers with ideas for sensitizing children without disabilities to the needs of children with disabilities.

Cohen, Shirley. *Accepting Individual Differences.* Niles, IL: Developmental Learning Materials, 1977. A set of five teaching guides and three children's books to help elementary students learn about disabilities.

Fallen, Nancy H.; McGovern, Jill E. *Young Children with Special Needs.* Columbus, OH: Charles E. Merrill Publishing Co., 1978. A resource for teachers and parents of young children who have disabilities.

Featherstone, Helen. *A Difference in the Family. Life With A Disabled Child.* New York: Basic Books, Inc. 1980. A moving book by the mother of a child with multiple disabilities about the feelings and emotions of parenting a child with disabilities.

Giedman, John; Roth, William. *The Unexpected Minority: Handicapped Children in America.* New York: Harcourt, Brace, Jovanich. 1980. Social rather than biological aspects of disabilities are analyzed.

Gordon, Sol. *Living Fully: A Guide for Young People with a Handicap, their Parents, their Teachers and Professionals.* New York, NY: The John Day Co., 1975.

Haring, Norris G. *Behavior of Exceptional Children.* (2nd ed.) Columbus, OH: Charles E. Merrill Publishing Co., 1978. An introduction to exceptional children and to the field of special education.

Hayden, Alice H.; Smith, Robert K.; Von Hippel, Caren Saaz; Baer, Sandra A. *Mainstreaming Preschoolers.* Washington, DC: U.S. Dept of HEW - Project Head Start, 1977. This series of books, which includes information on children with various disabilities, is a valuable resource to all preschool professionals and parents.

Hobbs, Nicholas. *Futures of Children: Issues in the Classification of Exceptional Children.* San Francisco, CA: Jossey-Bass Publishers, 1975. Excellent books from a major study on classification.

I Am, I Can, I Will. Series from the producers of Mister Roger's Neighborhood. Family Communications, Inc., 4802 5th Ave., Pittsburgh, PA, 1975. Published by Hubbard, P.O. Box 104, Northbrook, IL 60062. A series of video, audio and print materials for young children to acquaint them with differences.

Johnson, Richard A.; Weatherman, Richard F.; Rehmann, Arnold M. *Handicapped Youth and the Mainstream Educator.* Mpls., MN: The University of Minnesota, 1975. A proceedings of a Special Education Leadership Conference,

the book demonstrates a diversity of viewpoints on implications of mainstreaming.

Jones, Marilyn. *Exploring Computer Careers for the Handicapped.* New York, NY: Rosen Publishing Group, 1985. For people with visual, hearing, and orthopedic disabilities who want to learn about the education needed to get into computer careers, this small book offers information, descriptions, and a listing of training programs as of 1985.

Kappelman, Murray; Ackerman, Paul. *Between Parent and School.* New York, NY: Dial Press/James Wade, 1977. Excellent resource for parents and schools.

Long, Kate. *"Johnny's Such a Bright Boy, What a Shame He's Retarded"—In Support of Mainstreaming in Public Schools.* Boston, MA: Houghton, Mifflin Co., 1978. A fictional book about the need to integrate children with disabilities into regular classrooms.

McDonald, Eugene. *Understand Those Feelings: A Guide for Parents of Handicapped Children and Everyone Who Counsels Them.* Pittsburgh, PA: Stanivix House, 1977.

McNamara, Joan; McNamara, Bernard. *The Special Child Handbook.* New York, NY: Hawthorn Books, 1977. $12.50.

Moore, Coralie; Morton, Kathryn. U.S. Dept. of HEW, Public Health Service, Health Service, Health Service Administration Bureau of Community Health Service, Rockville, MD 20857. Write for a free single copy (DHEW publication HSA 77-5290). Excellent, annotated bibliography.

Payne, James S.; Kauffman, James M.; Patton, James R.; Brown, Gweneth B.; DeMott, Richard M. *Exceptional Children in Focus.* (2nd ed.) Columbus, OH: Chas. Merrill Publishing Co., 1979. This compact book gives basic information on disabilities, as well as concepts, issues, and trends.

Peiper, Elizabeth. *Sticks and Stones: The Story of Loving a Child.* Syracuse, NY: Human Policy Press, 1978. An excellent story of a search for help for a child with disabilities. Applicable to all people who have disabilities. Written by a parent.

People Just Like You. Committee on Youth Development, The President's Committee on Employment of People with Disabilities, Washington, DC, 1979. An excellent activity guide to help children learn about disabilities and persons with disabilities.

Reynolds, Maynard C. *Mainstreaming: Origins and Implications.* Reston, VA: Council for Exceptional Children.

Reynolds, Maynard C.; Birch, Jack W. *Teaching Exceptional Children in All America's Schools.* Reston, VA: The Council for Exceptional Children, 1977. A first course for teachers and principals.

Ross, Ruth-Ellen; Freelander, I. Robert. *Handicapped People in Society: A Curriculum Guide.* Burlington, VT: The University of Vermont, 1977. An excellent resource on influencing attitudes of children grades K-12 about disabling conditions.

Sullivan, Mary Beth; Brightman, Alan J.; Blatt, Joseph. *Feeling Free.* Reading, MA: Addison-Wesley Publishing Co., Inc., 1979. Five youngsters with various disabilities relate their feelings, as they did in the television series by the same name.

Summers, Jean Ann, ed. *The Right to Grow Up: An Introduction to Adults with Developmental Disabilities.* Baltimore, MD: Paul H. Brookes, 1986. This textbook should prove of interest to parents looking ahead. It explores the needs of adults with developmental disabilities, what services are necessary to meet those needs, and the self-advocacy, federal laws, and policies that will ensure that all needs will be met. Chapters include sexuality, marriage and parenthood, maintaining dignity in later years, residential and vocational options and issues, leisure and religious experiences, and independent living programs.

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Teacher Please Don't Close the Door—the Exceptional Child in the Mainstream. June B. Jordon, ed. Reston, VA: Council for Exceptional Children, 1979.

Turnbull, Ann P.; Rutherford, H. *Parents Speak Out: Views form the Other Side of the Two-Way Mirror.* Columbus, OH: Charles E. Merrill Publishing Co., 1978. A group of articles written by parents of children with disabilities who also are special education professionals.

Turnbull, Ann P.; Schulz, Jane B. *Mainstreaming Handicapped Students.* Boston, MA: Allyn and Bacon, Inc., 1979. A helpful book on techniques and practical ideas for teachers who have, or may in the future have children with disabilities in their classrooms.

Ward, Michael J.; Arkell, Robert N.; Dahl, Harry G.; Wise, James H. *Everybody Counts.* Reston, VA: The Council for Exceptional Children, 1979. A workshop manual to increase awareness of people with disabilities.

Weiner, Florence. *No Apologies: A Guide to Living with a Disability, Written by the Real Authorities-People with Disabilities, Their Families, and Friends.* New York, NY: St. Martin's, 1986. This fine collection of essays offers practical advice, lists of resources, and personal observations on a variety of subjects, including "living/making it with a disability," medical care, education, work and money, and organizing.

Wentworth, Elise M. *Listen to Your Heart: A Message to Parents of Handicapped Children.* Houghton, 1974. A superb book written by the mother of a child with disabilities, describing the feelings and reactions experienced by parents of children with disabilities. Offers sound, practical suggestions on how to deal with the feelings and problems encountered. Useful for both parents and teachers.

West, S. *Working with Parents of Handicapped Children.* Reston, VA: Educational Developmental Laboratory, Council for Exceptional Children, 1979.

Wodrich, David L. *Children's Psychological Testing: A Guide for Non-psychologists.* Baltimore, MD: Paul H. Brookes, 1984. The "nonpsychologists" referred to in the title are expected to be doctors, lawyers and teachers; parents, too, will find much of helpful interest in this description of what psychological tests actually measure, how they are organized, and what test scores mean. Over fifty of the tests most frequently used to evaluate children with learning disabilities, mental retardation, and emotional problems are described in nontechnical language.

Audio-visual Materials

A Child is a Child. (8 min., color) Produced and distributed by Franciscan Communications Center, 1229 Santee St., Los Angeles, CA 90015. Depicts the mainstreaming of preschoolers with disabilities and their understanding teachers.

A Matter of Inconvenience. (10 Min., color, 1974) by James Stanfield. Distributed by Stanfield House, 900 Euclid Ave., P.O. Box 3208, Santa Monica, CA 90403. Shows how individuals adapt to their disabilities.

A Touch of Hands (color) Using creative puppetry with disabled and able-bodied children, a sensitive art therapist demonstrates how to guide children towards a positive self-image and mutual acceptance of each other. Available from The Stanfield House, 12381 Wilshire Blvd., Suite 203, Los Angeles, CA 90025.

Feeling Free. (Series of films, 30 min. each, color) Produced and distributed by "Feeling Free," Workshop on Children's Awareness, 22 Hilliard St., Cambridge, MA 02138. In each of the films a young person talks about his or her disability, feelings, interests, etc.

Hello Everybody. (six color, sound filmstrips) Available from The Stanfield House, 12381 Wilshire Blvd., Suite 203, Los Angeles, CA 90025. Information about children who have disabilities.

I Am, I Can, I Will series from Mr. Roger's Neighborhood (audio-visual cassette materials) Information available from James Sequin, Family Communications, Inc., 4802-5th Ave., Pittsburgh, PA 15213.

Like You, Like Me. (10 films each 5-6 min. long, color, sound) Available from Encyclopedia Britannica Educational Corp., Chicago, IL 1977. Films help promote understanding and acceptance of children with disabilities.

Special Delivery. (Five individual 30 min. films for 7 - 10-year-old children, color, 1977.) Produced with funds from Bureau of Education for People with Disabilities by WNVT/Central Virginia Educational Television, Inc. Available from Lawren Productions, Inc., P.O. Box 666, Mendocino, CA 95460. Lively actions by puppets, persons with disabilities, and youngsters help viewers learn about disabilities and ways of relating to children with special needs.

Special Films on Young People with Disabilities, a list of 16mm films appropriate for elementary and secondary students and available for rental, can be ordered from University Film and Video, University of Minnesota, 1313-5th Street SE, Suite 108, Minneapolis, MN 55414; (612) 627-4270 or toll-free 1-800-542-0013.

Television Resources: (frequently features programs on disabilities) Sesame Street, Children's Television Workshop, 1 Lincoln Plaza, New York, NY 10023

Zoom. c/o GBH Educational Foundation, 125 Western Ave., Boston, MA 02134.

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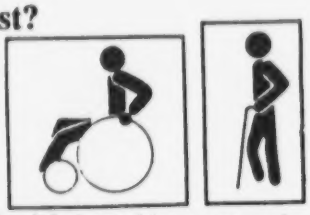
It's the 'Person First' - Then the Disability

What do you see first?

- *The wheelchair?*
- *The physical problem?*
- *The person?*



If you saw a person in a wheelchair unable to get up the stairs into a building, would you say "there is a handicapped person unable to find a ramp"? Or would you say "there is a person with a disability who is handicapped by an inaccessible building"?

What is the proper way to speak to or about someone who has a disability?

Consider how you would introduce someone — Jane Doe — who doesn't have a disability. You would give her name, where she lives, what she does or what she is interested in — she likes swimming, or eating Mexican food, or watching Robert Redford movies.

Why say it differently for a person with disabilities? Every person is made up of many characteristics — mental as well as physical — and few want to be identified only by their ability to play tennis or by their love for fried onions or by the mole that's on their face. Those are just parts of us.

In speaking or writing, remember that children or adults with disabilities are like everyone else — except they happen to have a disability. Therefore, here are a few tips for improving your language related to disabilities and handicaps.

1. Speak of the person first, then the disability.
2. Emphasize abilities, not limitations.
3. Do not label people as part of a disability group — don't say "the disabled"; say "people with disabilities."
4. Don't give excessive praise or attention to a person with a disability; don't patronize them.
5. Choice and independence are important; let the person do or speak for him/herself as much as possible; if addressing an adult, say "Bill" instead of "Billy."
6. A **disability** is a functional limitation that interferes with a person's ability to walk, hear, talk, learn, etc.; use **handicap** to describe a situation or barrier imposed by society, the environment or oneself.

Say...	Instead of...
child with a disability	disabled or handicapped child
person with cerebral palsy	palsied, or C.P., or spastic
person who has...	afflicted, suffers from, victim
without speech, nonverbal	mute, or dumb
developmental delay	slow
emotional disorder, or mental illness	crazy or insane
deaf or hearing impaired and communicates with sign	deaf and dumb
uses a wheelchair	confined to a wheelchair
person with retardation	retarded
person with epilepsy	retarded epileptic
with Down Syndrome	mongoloid
has a learning disability	is learning disabled
nondisabled	normal, healthy
has a physical disability	crippled
congenital disability	birth defect
condition	disease (unless it is a disease)
seizures	fits
cleft lip	hare lip
mobility impaired	lame
medically involved, or has chronic illness	sickly
paralyzed	invalid or paralytic
has hemoplegia (paralysis of one side of the body)	hemiplegic
has quadriplegia (paralysis of both arms and legs)	quadriplegic
has paraplegia (loss of function in lower body only)	paraplegic
of short stature	dwarf or midget

Reprinted from the June 1989 PACER Center Early Childhood Connection and September 1989 PACER Center PACESETTER.

Points to Remember When You Meet a Person Who Has a Disability

Remember that a person who has a disability is a person—like anyone else.

Relax. If you don't know what to do or say, allow the person who has a disability to help put you at ease.

Explore your mutual interests in a friendly way. The person likely has many interests besides those connected with the disability.

Offer assistance if asked or if the need seems obvious, but don't overdo it or insist on it. Respect the person's right to indicate the kind of help needed.

Talk about the disability if it comes up naturally without prying. Be guided by the wishes of the person with the disability.

Appreciate what the person can do. Remember that difficulties the person may be facing may stem more from society's attitudes and barriers than from the disability itself.

Be considerate of the extra time it might take for a person with a disability to get things said or done. Let the person set the pace in walking or talking.

Remember that we all have disabilities; on some of us they show.

Speak directly to a person who has a disability. Don't consider a companion to be a conversational go-between.

Don't move a wheelchair or crutches out of reach of a person who uses them.

Never start to push a wheelchair without first asking the occupant if you may do so.

When pushing a wheelchair up or down steps, ramps, or curbs, or other obstructions, ask the person how he or she wants you to proceed.

Don't lean on a person's wheelchair when talking.

Give whole, unhurried attention to the person who has difficulty speaking. Don't talk for the person, but give help when needed. Keep your manner encouraging rather than correcting. When necessary, ask questions that require short answers or a nod or shake of the head.

Speak calmly, slowly, and distinctly to a person who has a hearing problem or other difficulty understanding. Stand in front of the person and use gestures to aid communication. When full understanding is doubtful, write notes.

When dining with a person who has trouble cutting, offer to help if needed. (It may be easier to ask if the person would prefer to have the food cut in the kitchen.) Explain to a person who has a visual problem where dishes, utensils, and condiments are located on the table.

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Resource List of Disability Organizations

Minnesota Disability Organizations

ABLE (Association for Blind Living and Education), Room 105, 4139 Regent Ave. N., Robbinsdale, MN 55422, (612) 537-8000

Accessible Space, Inc. (ASI), Suite 301N, 2550 University Ave. W., St. Paul, MN 55114, (612) 645-7271

A Chance To Grow, (head trauma), 5034 Oliver Ave. N., Mpls., MN 55430, (612) 521-2266

ACT (Advocating Change Together), Room 363, Griggs Bldg., 1821 University Ave. W., St. Paul, MN 55104, (612) 641-0297 (advocacy for persons with mental retardation)

Adoptive Families of America, 3333 Hwy. 100 N., Mpls., MN 55422, (612) 535-4829

Advocate for the Blind, 4717 IDS Center, Mpls., MN 55402, (612) 330-3041

Alliance for the Mentally Ill of Minnesota, Inc., Suite 103, 1595 Selby Ave., St. Paul, MN 55104, (612) 645-2948

American Diabetes Association, Minnesota Affiliate, Inc. (ADAM), #307, 715 Florida Ave. S., Mpls., MN 55426-1759, (612) 593-5333

American Heart Association/Minnesota Affiliate, 4701 W. 77th St., Mpls., MN 55435, (612) 835-3300

American Lung Association of Hennepin County, 1829 Portland Ave. S., Mpls., MN 55404, (612) 871-7332

American Lung Association of Minnesota, 490 Concordia Ave., St. Paul, MN 55103, (612) 227-8014

American Lung Association of Ramsey County, 480 Concordia Ave., St. Paul, MN 55103, (612) 224-4901

Arthritis Foundation, MN Chapter, Suite 215, 122 Franklin Ave. W., Mpls., MN 55404, (612) 874-1201, **Outstate Toll-free:** 1-800-333-1380

Association of Residential Resources In Minnesota (ARRM), 26 E. Exchange St., St. Paul, MN 55101, (612) 291-1086

Arc Minnesota, 3225 Lyndale S., Mpls., MN 55408, for Arc contacts in 62 areas not listed, call (612) 827-5641, **Toll-free:** 1-800-582-5256

Arc Anoka County, 1100 90th Ave. NE, Blaine, MN 55434, (612) 780-0560

Arc Suburban, Suite 230, 15025 Glazier Ave., Apple Valley, MN 55124, (612) 431-3700

Arc Duluth, 201 Ordean Bldg., 424 W. Superior St., Duluth, MN 55802, (218) 726-4725

Arc Hennepin County, Room 140, 4307 Highway 7, Mpls., MN 55416, (612) 920-0855

Arc Olmsted County, #140, 903 W. Center St., Rochester, MN 55902, (507) 287-2032

Arc St. Croix Valley, P.O. Box 275, Stillwater, MN 55082, (612) 436-5784

Arc St. Paul, Suite 35, 425 Etna St., St. Paul, MN 55106, (612) 778-1414

Blind Inc., Suite 101, 33 S. 5th St., Mpls., MN 55402, (612) 339-8401

Candlelighters, American Cancer Society, MN Division, 3316 W. 66th St., Mpls., MN 55435, (612) 925-2772

Children's Mental Health Initiative (CMHI), 414 S. 8th St., Mpls., MN 55404 (to receive mailings on legislation, policy changes and meetings affecting children with emotional/behavioral disorders) (612) 340-7458

Coalition for the Education and Support of Attention Deficit Disorder (Co-ADD), P.O. Box 242, Osseo, MN 55369-0242, (612) 493-3177 (voice answering machine)

Comprehensive Hemophilia Center, U of MN Hospitals, UMHC-713, Harvard St. SE at E. River Rd., Mpls., MN 55455, (612) 626-6455

Courage Center, 3915 Golden Valley Rd., Golden Valley, MN 55422, (612) 588-0811 Voice, (612) 520-0410 TDD

Courage St. Croix, 1460 Curve Crest Blvd., Stillwater, MN 55082, (612) 439-8283

Cystic Fibrosis Foundation, Suite B10, 430 Oak Grove, Mpls., MN 55403, (612) 871-0462, **Toll-free:** 1-800-582-5245

Deafness Education and Advocacy Foundation (DEAF), #142, 419 N. Robert St., St. Paul, MN 55101, (612) 224-3156, (612) 224-2515 TDD

Epilepsy Foundation of Minnesota, 777 Raymond Ave., St. Paul, MN 55114-1522, (612) 646-8675, **Toll-free:** 1-800-779-0777

Feingold Association of Minnesota, 381 E. Cook St., St. Paul, MN 55101, (612) 774-8887 (for parents of children with hyperactivity and learning disabilities)

Human Growth Foundation, MN Chapter, Suite 315, 5701 Normandale Rd., Edina, MN 55424, (612) 925-5534 (physical growth problems)

International Diabetes Center, Park Nicollet Medical Foundation, 5000 W. 39th St., St. Louis Park, MN 55416, (612) 927-3393

In Touch, Inc., Suite 30, 1111 - 3rd Ave. S., Mpls., MN 55404, (612) 342-2066 Voice, (612) 342-2134 TDD (serving adults who are deaf-blind)

LEND, Inc. (Leaders in Educational Needs Development), P.O. Box 80685, Minneapolis, MN 55408, (612) 922-4544

Learning Disabilities Association, 2104 Park Ave. S., Mpls., MN 55404, (612) 871-9011

Learning Disabilities of Minnesota, Room 494 N., 1821 University Ave., St. Paul, MN 55104, (612) 646-6136

Legal Advocacy - *see* Minnesota Disability Law Center

Leukemia Society of America, 5217 Wayzata Blvd., St. Louis Park, MN 55416, (612) 545-3309

Lupus Foundation of America, Inc., MN Chapter, 640 - 11th Ave. S., Hopkins, MN 55343, (612) 933-4137

March of Dimes National Foundation for Birth Defects, Suite 268, 4940 Viking Dr., Edina, MN 55435, (612) 835-3033

MELD (Minnesota Early Learning Design) Special, 123 N. 3rd St., Mpls., MN 55401, (612) 332-7563

Mental Health Association of Minnesota, 328 E. Hennepin Ave., Mpls., MN 55414-1016, (612) 331-6840, **Toll-free:** 1-800-862-1799

Metro Center for Independent Living, Suite 303, 1619 Dayton Ave., St. Paul, MN 55104, (612) 646-8342 Voice/TDD

Center for Independent Living of NE MN, Inc., 2310 - 1st Ave., Hibbing, MN 55746, (218) 262-6675

Central MN Center for Independent Living, Suite 109, 600 - 25th Ave. S., St. Cloud,MN 56301, (612) 255-1882

Options for Independent Living, Holiday Mall, 211 Demers Ave., East Grand Forks, MN 56721, (218) 773-6100

Rural Enterprise for Acceptable Living, Inc. (REAL), 244 W. Main St., Marshall, MN 56258, (507) 532-2221

SE Minnesota Center for Independent Living, Inc., 1306 - 7th St. NW, Rochester, MN 55901, (507) 285-1815, (507) 285-1704 TDD

Metropolitan Association for the Hearing Impaired, Carolyn Anderson, 3142 Quail Ave. N., Golden Valley, MN 55422, (612) 521-8416 Voice/TDD

MINCEP Epilepsy Care P.A., Suite 255, 5775 Wayzata Blvd., Mpls., MN 55416, (612) 525-1160, **FAX:** (612) 525-1560

Minnesota Association of the Deaf, 1824 Marshall Ave., St. Paul, MN 55104, (612) 644-3455

Minnesota Association of Parents of Visually Impaired (MAPVI), Fraser School, 2400 W. 64th St., Mpls., MN 55423, (612) 861-1688

Minnesota Association of Rehabilitation Facilities (MARF), Room 376 S., 1821 University Ave. W., St. Paul, MN 55104, (612) 646-0900

Minnesota Chemical Dependency Program for Hearing Impaired Youth, Riverside Medical Center, Riverside at 25th Ave. S., Mpls., MN 55455, (612) 337-4402 Voice, (612) 337-4114 TDD, **Nationwide Toll-free:** 1-800-282-DEAF Voice/TDD

Minnesota Coalition on Handicap Issues, 2527 Monterey Ave. S., St. Louis Park, MN 55416, (612) 922-4544 (umbrella organization for legislation)

Minnesota Committee for the Prevention of Child Abuse, Suite 191, 1821 University Ave., St. Paul, MN 55104, (612) 641-1568

Minnesota Council for the Gifted and Talented, Room 309, 5701 Normandale Rd., Edina, MN 55424, (612) 927-9546

Minnesota Developmental Achievement Center Association (MN DACA), Suite 277 S., 1821 University Ave., St. Paul, MN 55104, (612) 647-9200

Minnesota Disability Law Center (previously called Legal Advocacy for Persons with Developmental Disabilities), 222 Grain Exchange Bldg., 323 4th Ave. S., Mpls., MN 55415, (612) 338-0968, 332-1441, **Outstate Toll-free:** 1-800-292-4150 (free legal services for persons who are developmentally disabled)

Minnesota Foundation for Better Hearing and Speech, St. Paul Community Services Bldg., Suite 320, 166 E. 4th St., St. Paul, MN 55101-1400, (612) 223-5130 Voice/TDD

Minnesota Head Injury Association, Suite 311, 1313 - 5th St. SE, Mpls., MN 55414, (612) 379-3911 Voice/TDD

Minnesota Radio Talking Book Network, Communication Center, 1745 University Ave., St. Paul, MN 55104, (612) 642-0502 (a free closed circuit radio reading service and special library services, leisure and educational)

Minnesota Special Olympics, Inc., Suite 1430, 625 - 4th Ave. S., Mpls., MN 55415, (612) 333-0999

Minnesota Speech-Language-Hearing Association, P.O. Box 26115, St. Louis Park, MN 55426, (612) 935-5057

Minnesota West-Metro Chapter, National Society for Autistic Children, 5624 - 73rd Ave. N., Brooklyn Park, MN 55429, (612) 560-5330

Muscular Dystrophy Association, Room 164, 4530 W. 77th St., Mpls., MN 55435, (612) 832-5517, **St. Paul Office:** Room 144, 4530 W. 77th St., Mpls., MN 55435, (612) 832-5716

National Ataxia Foundation, 600 Twelve Oak Center, 15500 Wayzata Blvd., Wayzata, MN 55391, (612) 473-7666

National Federation of the Blind of Minnesota, Inc., Chamber of Commerce Bldg., Suite 715, 15 S. 5th St., Mpls., MN 55402, (612) 332-5414

National Hemophilia Foundation, MN Chapter, 2304 Park Ave. S., Mpls., MN 55404, (612) 871-3340

National Kidney Foundation of the Upper Midwest, Inc., 620 S. 10th Ave., Mpls., MN 55415, (612) 337-7300

National Multiple Sclerosis Society, MN North Star Chapter, Suite 280, 2344 Nicollet Ave S., Mpls., MN 55404-3381, (612) 870-1500, **Toll-free:** 1-800-582-5296

North Suburban Consumer Advocates for the Handicapped, 200 Charles St. NE, Fridley, MN 55432, (612) 571-6855

Osteogenesis Imperfecta Foundation, Inc., 2 W. St. Albans Rd., Hopkins, MN 55343, (612) 936-0946

PACER Center, Inc., (Parent Advocacy Coalition for Educational Rights), 4826 Chicago Ave. S., Mpls., MN 55417-1055, (612) 827-2966 Voice/TDD, (parents in greater Minnesota may call **Toll-free:** 1-800-53PACER), **FAX:** (612) 827-3065

Parents of Cleft Children, Minnesota Department of Health, P.O. Box 9441, 717 Delaware St. SE, Mpls., MN 55414, (612) 623-5174

PATH (Professional Association of Treatment Homes) Metro Office, #200, 1730 Clifton Place, Mpls., MN 55403, (612) 871-4314

Parents for Heart, 410 Zinnia Lane N., Plymouth, MN 55441, (612) 545-5562

Pathfinder Resources, Inc., Suite 105, 2324 University Ave. W., St. Paul, MN 55114, (612) 647-6905

Pilot Parents—Minnesota, 201 Ordean Bldg., 424 W. Superior St., Duluth, MN 55802, (218) 726-4745

Pilot Parent Centers:

Mid-State Pilot Parents, P.O. Box 1536, St. Cloud, MN 56302, (612) 253-6844

Pilot Parents of NE MN, 1201 S. 8 1/2 St., P.O. Box 7066, Virginia, MN 55777, (218) 749-8273

Pilot Parents in Ramsey County, Suite 35, 425 Etna St., St. Paul, MN 55106, (612) 778-0727, (612) 778-0738 TDD

Prader-Willi Syndrome Association, Suite E102, 6490 Excelsior Blvd., St. Louis Park, MN 55426, (612) 926-1947

Self Help for Hard of Hearing, Inc., Minnesota Chapter #1, 831 Second Ave. S., Mpls., MN 55403, (612) 332-4238 or 722-9178

Sick Kids Need Involved People, Inc. (SKIP), 11208 Minnetonka Mills Rd., Minnetonka, MN 55343, (612) 935-6433

Spina Bifida Association of Minnesota, P.O. Box 29323, Brooklyn Center, MN 55429, (612) 222-6395, **Toll-free:** 1-800-621-3141

Tourette Syndrome Association, MN Chapter, 835 Millwood Ave. N., Roseville, MN 55113, (612) 481-8910

Tuberous Sclerosis in Minnesota, 2986 N. Howard St., Maplewood, MN 55109, (612) 777-4833

Twin Cities Down Syndrome Association, Fraser Community Services, 2400 W. 64th St., Mpls., MN 55423, (612) 861-1688

Twin Cities Society for Children and Adults with Autism, 253 E. 4th St., St. Paul, MN 55101 (612) 228-9074

United Cerebral Palsy of Minnesota, Inc., Suite 233 S., 1821 University Ave., St. Paul, MN 55104, (612) 646-7588

UCP Central Minnesota, 37 - 28th Ave. N., St. Cloud, MN 56303, (612) 253-0765

UCP Northeast Minnesota, #402, 424 W. Superior St., Duluth, MN 55802, (218) 726-4723

United Handicapped Federation, Suite 284 S., 1821 University Ave., St. Paul, MN 55104, (612) 645-8922 Voice/TDD

Very Special Arts Minnesota, Suite 201, 528 Hennepin Ave. Minneapolis, MN 55403, (612) 332-3888

Minnesota State Disability Agencies

Deaf Services Division, Department of Human Services, Human Services Bldg., 444 Lafayette Rd., St. Paul, MN 55155-3814, (612) 296-3980 Voice, (612) 297-1506 (ONLY TDD)

Developmental Disabilities Program, Metropolitan Council, Mears Park Centre, 230 E. 5th St., St. Paul, MN 55101, (612) 291-6364

Division of Rehabilitation Services (DRS), Fifth Floor, 390 N. Robert St., St. Paul, MN 55101, (612) 296-5616

Interagency Planning Project for Young Children with Handicaps, 830 Capitol Square Bldg., 550 Cedar St., St. Paul, MN 55101, (612) 296-7032

Minnesota Department of Health Services for Children with Handicaps (SCH), 717 Delaware St. SE, P.O. Box 9441, Mpls., MN 55440, (612) 623-5150 Voice/TDD, **Toll-free:** 1-800-728-5420

Minnesota Department of Human Services, 444 Lafayette Rd., St. Paul, MN 55155, (612) 296-6117 (Developmental Achievement Centers, Day Care and Nursery Schools licensed by Department of Human Services)

Minnesota Governor's Planning Council on Developmental Disabilities, 300 Centennial Office Bldg., 658 Cedar St., St. Paul, MN 55155, (612) 296-4018

Minnesota Resource Center for the Blind & Visually Impaired, P.O. Box 68, Faribault, MN 55021, (507) 332-3219, **Toll-free:** 1-800-652-9747

Minnesota Resource Center: Hearing Impaired, P.O. Box 308, Faribault, MN 55021, (507) 332-3478 or **Toll-free:** (800) 652-9747

Minnesota State Council on Disability, 145 Metro Square Bldg., 7th Place & Jackson St., St. Paul, MN 55101, (612) 296-6785 Voice/TDD, **Toll-free:** 1-800-652-9747

Minnesota State Department of Education, Unique Learner Needs Section (Special Education), 809 Capitol Square Bldg., 550 Cedar St., St. Paul, MN 55101, (612) 296-4163

Office of Compliance and Monitoring, Minnesota Department of Education, 528 Capitol Square, 550 Cedar St., St. Paul, MN 55101, (612) 297-2843

Ombudsman for Mental Health & Mental Retardation, Suite 202, Metro Square Building, St. Paul, MN 55101, (612) 296-3848 or **Toll-free:** 1-800-652-9747

Regional Service Center for Hearing Impaired People:

Crookston - Hillview Offices, Hwy. #75 & Minnesota St., Crookston, MN 56716, (218) 281-1946 Voice/TDD

Duluth - Government Service Center, Suite 611, 320 W. Second St., Duluth, MN 55802, (218) 723-4962 Voice, (218) 723-4961 TDD

Fergus Falls - Suite 7, 125 W. Lincoln Ave., Fergus Falls, MN 56537, (218) 739-7589 Voice, (218) 739-7591 TDD

Mankato - Nichols Office Center, Suite 480, 410 Jackson St., Mankato, MN 56001, (507) 389-6517 Voice, (507) 389-5361 TDD

Metro - Human Services Bldg., 444 Lafayette Rd., St. Paul, MN 55155-3814, (612) 297-1316 Voice, (612) 297-1313 TDD

Rochester - Suite 140, 1200 S. Broadway, Rochester, MN 55904, (507) 285-7295 Voice, (507) 285-7172 TDD

St. Cloud - Suite 100, 3341 W. St. Germain St., St. Cloud, MN 56301, (612) 255-3502 Voice, (612) 255-3590 TDD

Virginia - Suite 100, 820 N. 9th St., Virginia, MN 55792, (218) 741-5855 Voice/TDD

Willmar - 2015 S. 1st St., Willmar, MN 56201, (612) 231-5175 Voice/TDD

Services for Children with Handicaps, Minnesota Department of Health, P.O. Box 9441, 717 SE Delaware St., Mpls., MN 55440, (612) 623-5150, (Provides evaluation of children with disabilities from birth-21 and may pay for treatment, if they qualify financially and medically)

State Services for the Blind and Visually Handicapped, 1745 University Ave. W., St. Paul, MN 55104-3690, (612) 642-0500

National Disability Organizations And Agencies

Alexander Graham Bell Association for the Deaf, 3417 Volta Place NW, Washington, DC 20007, (202) 337-5220 Voice/TDD

American Association on Mental Retardation, 1719 Kalorama Rd. NW, Washington, DC 20009-2684, (202) 387-1968, **Toll-free:** 1-800-424-3688

American Association of University Affiliated Programs for Persons with Developmental Disabilities, Suite 410, 8630 Fenton St., Silver Spring, MD 20910, (301) 588-8252

American Council of the Blind, Suite 1100, 1010 Vermont Ave. NW, Washington, DC 20005, (202) 393-3666, **Toll-free:** 1-800-424-8666

American Foundation for the Blind, 15 W. 16th St., New York, NY 10011, (212) 620-2000 or (800) 232-5463, (212) 620-2158 TDD

American Speech-Language-Hearing Association, 10801 Rockville Pike, Rockville, MD 20852, (301) 897-5700; **Consumer Affairs Division, Toll-free:** 1-800-638-8255 Voice/TDD

Association for the Care of Children's Health (ACCH), Suite 300, 7910 Woodmont Ave., Bethesda, MD 20814, (301) 654-6549

Autism National Committee, 7 Teresa Circle, Arlington, MA 02174, (407) 795-1894, (617) 648-1813

Autism Society of America, Inc., Suite 503, 8601 Georgia Ave., Silver Spring, MD 20910, (301) 565-0433

Beach Center on Families and Disability, Bureau of Child Research, University of Kansas, 4138 Haworth Hall, Lawrence, KS 66045, (913) 864-7600 or 4950

Better Hearing Institute, Hearing Helpline, P.O. Box 1840, Washington, DC 20013, **Toll-free:** 1-800-424-8576

Cancer Information Service, Toll-free: 1-800-4-CANCER (National Line)

The Candlelighters, Childhood Cancer Foundation, 2nd Floor, 1312 -18th St. NW, Washington, DC 20036

Center for Law and Education, Larsen Hall, 6th Floor, 14 Appian Way, Cambridge, MA 02138, (617) 495-4666

Child and Adolescent Service System Program (CASSP), National Institute of Mental Health (NIMH), Parklawn Building Room 7C-14, 5600 Fishers Lane, Rockville, MD 20857, (301) 443-1333

Children with Attention Deficit Disorder (CH.A.D.D.), Suite 308, 499 NW 70th Ave., Plantation, FL 33317, (305) 287-3700 (national support group)

Children's Defense Fund, Suite 400, 122 C St. NW, Washington, DC 20001, (202) 628-8787

Council for Exceptional Children (CEC), 1920 Association Dr., Reston, VA 22091, (703) 620-3660

Disability Rights Center, 1345 Connecticut Ave. NW, Washington, DC 20036, (202) 223-3304

Disability Rights Education and Defense Fund (DREDF), 2212 6th St., Berkeley, CA 94710, (415) 644-2555

Epilepsy Foundation of America (and National Epilepsy Library and Resource Center), Suite 406, 4351 Garden City Dr., Landover, MD 20785, (301) 459-3700, **Toll-free:** 1-800-EFA-1000

ERIC Clearinghouse on Adult Career & Vocational Education, 1960 Kenny Rd., Columbus, OH 43210, **Toll-free:** 1-800-848-4815

ERIC Clearinghouse on Handicapped and Gifted Children, 1920 Association Dr., Reston, VA 22091, (703) 620-3660, **FAX:** (703) 264-9494

Federation for Children with Special Needs, Suite 104, 95 Berkeley St., Boston, MA 02116, (617) 482-2915

Federation for Families for Children's Mental Health, 1021 Prince Street, Alexandria, VA 22314-2971, (703) 684-7710

Helen Keller National Center for Deaf-Blind Youth (HKNC)/Technical Assistance Center, 111 Middle Neck Road, Sands Point, NY 11050, (516) 944-8900 Voice/TDD

Human Growth Foundation, 4720 Montgomery Lane, Bethesda, MD 20814, (301) 656-7540, **Toll-free:** 1-800-451-6434

Immune Deficiency Foundation, Box 586, Columbia, MD 21045, (301) 461-3127

Institute for Families of Blind Children, Children's Hospital of Los Angeles, Division of Ophthalmology, Room III, P.O. Box 54700, Los Angeles, CA 90054-0700, (213) 669-4669

Learning Disabilities Association of America, 4156 Library Rd., Pittsburgh, PA 15234, (412) 341-1515, 314-8077

Leukemia Society of America, 14th Floor, 733 Third Ave., New York, NY 10017, (212) 573-8484

Linc Resources, Inc., 3857 N. High St., Columbus, OH 43214, (614) 263-5462 (information center for special education media and materials)

Little People of America, P.O. Box 9897, Washington, DC 20016

Lowe's Syndrome Association, 222 Lincoln St., West Lafayette, IN 47906, (317) 743-3634

Lupus Foundation of America, Inc., Suite 203, 1717 Massachusetts Ave. NW, Washington, DC 20036, **Toll-free:** 1-800-558-0121

March of Dimes Birth Defects Foundation, 1275 Mamaroneck Ave., White Plains, NY 10605, (914) 428-7100

Mental Health Law Project, Suite 800, 2021 L St. NW, Washington, DC 20036, (202) 467-5730

Mexican-American Legal Defense Fund, 10th Floor, 604 Mission St., San Francisco, CA 94105, (415) 543-5598

Muscular Dystrophy Association, 810 Seventh Ave., New York, NY 10019, (212) 586-0808

National Alliance for the Mentally Ill, Suite 500, 1901 Fort Meyer Dr., Arlington, VA 22209, (703) 524-7600

National Association of the Deaf, 814 Thayer Ave., Silver Spring, MD 20910, (301) 587-1788 Voice/TDD

National Association for Retarded Citizens, 2501 Avenue J, Arlington, TX 76006, (817) 640-0204

National Association of State Directors of Special Education, Suite 315, 2021 K St. NW, Washington, DC 20006, (202) 296-1800

National Center for Clinical Infant Programs, Suite 912, 733 - 15th St. NW, Washington, DC 20005, (202) 347-0308

National Center for Education in Maternal & Child Health (NCEMCH), 38th & R Streets NW, Washington, DC 20057, (202) 625-8400

National Center for Law and the Deaf, 800 Florida Ave. NE, Washington, DC 20002, (202) 651-5454

National Center for Stuttering, 200 E. 33rd St., New York, NY 10016, **Toll-free:** 1-800-221-2483

National Center for Youth with Disabilities, Adolescent Health Program, University of Minnesota, Box 721-UMHC, Harvard St. at E. River Road, Mpls., MN 55455, (612) 626-2825, **Toll-free:** 1-800-333-6293

National Chronic Pain Outreach Association (NCPOA), 4922 Hampden Lane, Bethesda, MD 20814, (301) 652-4948

National Council on the Handicapped, Suite 814, 800 Independence Ave. SW, Washington, DC 20591, (202) 267-3846

National Down Syndrome Congress, 1800 Dempster St., Park Ridge, IL 60068-1146, (312) 823-7550, **Toll-free:** 1-800-232-NDSC

National Down Syndrome Society, 666 Broadway, New York, NY 10012, (212) 460-9330, **Toll-free:** 1-800-221-4602

National Easter Seal Society, 70 E. Lake St., Chicago, IL 60601, (312) 726-6200

National Federation of the Blind, Suite 300, 655 - 15th St. NW, Washington, DC 20005, (202) 639-4028

National Head Injury Foundation, 333 Turnpike Rd., Southboro, MA 01772, (508) 485-9950, **Toll-free:** 1-800-444-6443

National Health Information Center (Office of Disease Prevention and Health Promotion), P.O. Box 1133, Washington, DC 20013-1133, **Toll-free:** 1-800-336-4797

National Hearing Aid Society, 20361 Middle Belt Rd., Livonia, MI 48152, (313) 478-2610, **Toll-free:** 1-800-521-5247

National Information Center for Handicapped Children and Youth (NICHCY), Mail Address: P.O. Box 1492, Washington, DC 20013, **Business Address:** Suite 1100, 7926 Jones Branch Dr., McLean, VA 22102, (703) 893-6061

National Information Clearinghouse for Infants with Disabilities and Life-Threatening Conditions, CDD/USC, Benson Building, First Floor, Columbia, SC 29208, (803) 777-4435, **Toll-free:** 1-800-922-9234

National Institute on Disability and Rehabilitation Research (NIDRR), Department of Education, 400 Maryland Ave. SW, Washington, DC 20202, (202) 732-1196

National Library Service for the Blind and Physically Handicapped, The Library of Congress, 1291 Taylor St. NW, Washington, DC 20542, (202) 707-5100

National Mental Health Association, 1021 Prince St., Alexandria, VA 22314-2971, (703) 684-7722

National Multiple Sclerosis Society, 205 E. 42nd St., New York, NY 10017-5706, (212) 986-3240, **Toll-free:** 1-800-637-6303

National Organization for Albinism & Hypopigmentation (NOAH), Suite 1816, 1500 Locust St., Philadelphia, PA 19102, (215) 545-2322

National Organization for Rare Diseases, P.O. Box 8923, New Fairfield, CT 06812, (203) 746-6518, **Toll-free:** 1-800-999-NORD

National Parent Network on Disabilities, Room 115, 1600 Prince St., Alexandria, VA 22314, (703) 684-6763

National Rehabilitation Information Center (Computer Information Service called ABLEDATA), Suite 935, 8455 Colesville Rd., Silver Spring, MD 20910, **Toll-free:** 1-800-346-2742

National Resource Institute on Children with Handicaps (NRICH), University of Washington, Mail Stop WJ-10, Seattle, WA 98195, (206) 543-2254

National Spinal Cord Injury Association, 369 Elliot St., Newton Upper Falls, MA 02164

National Tay-Sachs & Allied Diseases Association, Inc., 122 E. 42nd St., New York, NY 10017, (212) 661-2780

Office for Civil Rights National Office, Department of Education, Room 5000, Switzer Bldg., 400 Maryland Ave. SW, Washington, DC 20202

Office of Civil Rights, Region 5 Office, Department of Education, Room 700C, 401 S. State St., Chicago, IL 60605-1202, (312) 886-3456

Office of Special Education Programs (OSEP), Switzer Bldg., 400 Maryland Ave. SW, Washington, DC 20202-2651, (202) 732-1032

Office of Special Education & Rehabilitative Services (OSERS), Room 3018 Switzer Bldg., 330 C St. SW, Washington, DC 20202, (202) 732-1723, 1245

Protection and Advocacy for Mentally Ill Program (PAMI), National Institute of Mental Health, Rm. 11C-17, 5600 Fishers Lane, Rockville, MD 20857, (301) 443-3667

Resource Access Project (RAP), 240 Col. Wolfe School, 403 E. Healey, Champaign, IL 61820, (217) 333-3876 (network for Head Start)

Schools Are For Everyone (SAFE), Suite 171-E, 7800 Shoal Creek Blvd., Austin, TX 78757

Self Help for Hard of Hearing, Inc., 7800 Wisconsin Ave., Bethesda, MD 20814, (301) 657-2248

Sick Kids Need Involved People, Inc. (SKIP), 216 Newport Dr., Severna Park, MD 21146, (301) 647-0164

Spina Bifida Association of America, Suite 540, 1700 Rockville Pike, Rockville, MD 20852, (301) 770-7222, **Toll-free:** 1-800-621-3141

Technical Assistance for Parent Programs (TAPP), Federation for Children with Special Needs, 95 Berkeley St., Boston, MA, (617) 482-2915

The Association for Persons with Severe Handicaps (TASH), 7010 Roosevelt Way NE, Seattle, WA 98115, (206) 523-8446

United Cerebral Palsy Association, Suite 804, 7 Penn Plaza, New York, NY 10001, (212) 481-6300

World Institute on Disability, 510 - 16th St., Oakland, CA 94612, (415) 486-8314